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Community Residential Services

for developmentally handicapped people

Program Development Series
Volume IV

42 ✓

PROGRAM DEVELOPMENT SERIES

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Policy and Program Development Division
Ministry of Community
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PREFACE

In October of 1982, details of a Five Year Plan for the expansion of services and consolidation of facilities for developmentally handicapped people in Ontario were announced by the Ministry of Community and Social Services. This preface introduces a paper entitled, Community Residential Services for Developmentally Handicapped People. The paper discusses a number of issues raised by the experience of the last decade in developing residential services in the community, and forms an important component of the Five Year Plan.

This Five Year Plan is a continuation of a policy introduced in 1973 to provide a fuller life in the community for developmentally handicapped children and adults. It proposes to increase the number of residential places in the community over the next five years and to provide residential services to more severely disabled persons. The paper has two general objectives that are closely related to the Five Year Plan: to resolve problems in the operation of residential programs and improve and contribute to future planning for residential services; and to provide guidelines regarding the models of residential care appropriate to the special needs of developmentally handicapped individuals who are severely disabled.

Services for developmentally handicapped people have undergone significant changes during the past decade. Some of the major achievements of the cooperation between the Ministry of Community and Social Services and the Ontario Association for the Mentally Retarded, its local affiliates and other agencies in the field of developmental handicap are outlined below.

Since 1975, approximately 2,800 new residential places for children and adults have been developed while the capacity of workshop and training programs has more than doubled. One hundred and thirty Adult Protective Service Workers now provide support to over 6,000 developmentally handicapped adults who are coping with the day-to-day activities of independent living.

A variety of services have also been created for developmentally handicapped children and their families. These include parent relief, the Family Support Worker program, developmental day care centres and the "special needs and services" program.

The present paper looks specifically at the residential component of the network of services we now have in place in communities throughout the province. The paper makes recommendations concerning the auspices under which community residences are operated and suggests means by which government and agencies can increase community acceptance of group homes. The process of admissions to residential programs, evaluation and the funding of programs are also discussed in the paper. And finally the paper sets out a range of residential options that provide an oportunity for clients to live in a family-like atmosphere or with a small number of peers. The specific needs of severely disabled and multihandicapped people including the behaviorally/emotionally disturbed, and sensory impaired people are examined, as are the special needs of aging developmentally handicapped individuals.

This document was prepared for public release to indicate the general directions in which the Ministry wishes to go with respect to residential services for developmentally handicapped persons. It also presents for discussion some specific program guidelines designed to assist in the development of high quality, effective residential programs. As resources and opportunities permit, Ministry policy will be to proceed with these general directions as outlined.

Community Residential Services for Developmentally Handicapped People is the fourth volume in a Program Development Series. (See reverse side of the title page for a list of other papers in the series and for information on how to obtain additional copies). Agencies providing residential services to developmentally handicapped people and all interested parties are invited to comment on the document.

A meeting will be held in your area within the next few months at which time you will have an opportunity to discuss this paper as well as other papers in the Program Development Series with Ministry staff. We welcome written responses which should be forwarded to your local MCSS Area Office.

TABLE OF CONTENTS

		Page
	Introduction	1
Chapter I	Sponsorship and Operational Responsibility	4
Chapter II	Zoning and Community Acceptance	11
Chapter III	Admission and Discharge Procedures	15
Chapter IV	Evaluation of Residential Services	19
Chapter V	General Models of Residential Services	26
Chapter VI	The Funding of Community Residences	32
Chapter VII	Residential Services for Mildly and Moderately Retarded Persons	40
Chapter VIII	Residential Services for Elderly Mentally Retarded Persons	43
Chapter IX	Residential Services for Emotionally/Behaviorally Disturbed Persons	49
Chapter X	Residential Services for Sensory Impaired Persons	57
Chapter XI	Residential Services for Severely and Profoundly Retarded and Multihandicapped Persons	65
Chapter XII	Coordination with Other Services	73
	Selected Bibliography	76
Appendix 1	The Operation of Community Residential Programs for the Developmentally Handicapped	1
2	The Group Home Policies of Ontario Municipalities	3
3	Responsibility for Group Homes	7
4	Proposed Clarification of the "50/50 Rule" for Admissions to Group Homes for the Developmentally Handicapped	8
5	Alternative Means of Measuring the Level of Service Required by Individuals in Residential Care	9
6	An Example of an Instrument for Measuring Levels of Disability	12
7	Estimated Costs for Various Models of Residential Care by Level of Disability	38
8	Needs of the Elderly Retarded	44
9	Types of Behavioral/Emotional Disturbances among the Developmentally Handicapped: One Approach to Classification	46

10 Environmental Analysis and Problem Behavior 47

11 Advantages and Disadvantages of Moving Disturbed/Disturbing Clients to Specialized Residences 49

12 Specialized Residential Services Now Available in Ontario for People Who Are Sensory-Impaired and Developmentally Handicapped 51

13 The Needs of Multihandicapped Clients 54

14 Descriptions of Physical Handicaps Frequently Associated with Profound Retardation 57

15 Case Histories: Three Profoundly Multihandicapped Persons 63

16 Areas of Program Emphasis for Profoundly Retarded Persons 66

INTRODUCTION

In 1973 the Government of Ontario adopted a policy focus for the delivery of services to developmentally handicapped persons. Centered on the concept of community living, it was a response to the reports titled Present Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario (Williston, 1971) and Community Living for the Mentally Retarded in Ontario (Welch, 1973). The five-year Implementation Plan ("the Blue Book"), approved by Cabinet in 1975, provided detailed proposals for the development of community-based accommodations, as well as work, training, and support services.

The plan was designed to focus on the most critical needs first, and community group homes for adults was one of the major areas of expansion. Almost 3000 beds for adults have become operational to date. The development of community homes for children has proceeded more slowly and now numbers approximately 500 beds. In total, the number of community residential places increased from 1000 in 1975 to nearly 3500 by 1982.

OBJECTIVES OF THE PAPER

The paper has two general objectives. Firstly, it attempts to deal with a number of issues raised by the experience of the last decade in providing community residential services. The recently completed Five Year Plan proposes to increase the number of residential places in the community, making resolution of these issues essential not only to the improved effectiveness of existing programs, but also to the planning of future residential developments.

The Five Year Plan also proposes to provide residential services to more severely disabled persons. Therefore, the second general objective is to draw on the experience in Ontario and elsewhere to develop models of residential care appropriate to the varied needs of this group of clients.

The specific objectives of the paper are to:

1. Clarify the auspices under which residences can be operated, particularly with respect to the role of the government and the role of for-profit operators, if any.
2. Deal with issues relating to community acceptance and zoning.
3. Assist residential programs to fulfill their mandate in terms of admission criteria and processes.
4. Develop approaches which can also assist residential programs to increase their effectiveness in meeting individualized goals and objectives and which can also assist programs to improve the quality of life provided to residents.
5. Propose steps to ensure that residential programs are using their financial and human resources effectively, and that they are providing services that meet standards of quality of care.
6. Develop more appropriate and flexible operating and capital funding formulas that are closely linked to the needs of individual residents, and that permit the provision of residential services at reasonable cost.
7. Develop a range of residential options that provide an opportunity for clients to live in a family-like atmosphere or with a small number of peers.
8. Develop models of residential services for more severely disabled and multihandicapped persons and for those with special needs, such as the behaviorally/emotionally disturbed, the sensory-impaired, and the aged.
9 Promote coordination between the services provided by residential programs and those provided by day programs and support programs.

THE DEVELOPMENT OF THE PAPER

Terms of reference for a task force to make recommendations on residential issues and on the types of community residential services which should be available to developmentally handicapped persons were approved by MCSS Senior Management Committee in 1980. The task force included representation from both central and area offices of Adults' and Children's Divisions, as well as representatives from the Facilities Division and the Ontario Association for the Mentally Retarded. The directions proposed in this paper reflect the discussions of this task force.

PRINCIPLES OF RESIDENTIAL SERVICES DELIVERY

Before exploring ways of achieving these objectives, it is important to highlight the purpose and principles of Ontario's residential services for the developmentally handicapped.

The primary purpose is to provide homes that promote and nurture the mental, physical, emotional, and social development of each individual. Inherent in this commitment is the responsibility to provide the environment that will enable the individual to: (1) live a personally satisfying life (2) develop his or her physical, intellectual, social, and emotional capabilities to the fullest extent possible; and (3) develop the skills, habits, and attitudes essential to living in present-day society.

Principles

These goals can best be achieved by ensuring that certain principles underlie the delivery of all services. These principles, while general in nature, are designed to provide a framework for judging specific issues regarding service planning and delivery. They are consistent with principles outlined in a number of MCSS documents, including Community Services to the Developmentally Handicapped: Principles and Guidelines, (1979) as well as with a number of position statements of the Canadian and Ontario Associations for the Mentally Retarded and the National Association for Retarded Citizens.

1. ***A residence should be regarded primarily as the home of the people who live there.***

   This would mean, for example, that when residents' needs change, consideration should be given to a relocation or changed use of staff as an alternative to movement of the resident.

2. ***Residential services should promote a normal life style.***

   Developmentally handicapped children and adults should be helped to live as normal a life as possible. The structuring of daily routines, the quality and style of life, and the nature of the physical environment should approximate the normal cultural pattern to the greatest extent possible. In general, this is most effectively achieved by including the individual within the mainstream of society.

3. ***Residential services should include programs that are developmental in nature and that meet the needs of each resident.***

   All developmentally handicapped children and adults are capable of learning and development. Each individual has potential for progress, no matter how severely handicapped he or she may be. Programs and program objectives must be designed to meet the requirements of individuals, not the other way around.

The overall program for each developmentally handicapped person must meet three basic criteria:

(a) It increases the complexity of the individual's behavior.
(b) It increases the individual's ability to control his or her environment.
(c) It maximizes those qualities that have been designated as "normal"

4. *Programs for developmentally handicapped persons should use the established community services to the fullest extent.*

Use of community services provides opportunities for the developmentally handicapped person to experience a broad array of social situations that can contribute to learning new skills and increasing independence. The developmentally handicapped child should be educated in the regular community schools, and the developmentally handicapped adult should, whenever possible, work in regular community employment. Every effort should be made to use community medical, dental, family support, and recreational resources to meet the needs of developmentally handicapped people.

5. *A spectrum of residential services should be accessible to persons residing in all geographic areas of Ontario.*

Developmentally handicapped persons should be provided only those services and supervision necessary to foster normal living. Providing more services and supervision than required only serves to discourage or limit the developmental growth of the individual. An individual who can no longer profit from and does not need a program should be provided with a route out of the system.

6. *Residential programs should promote client and family participation.*

Programs must take the individual's personal goals into account. Most developmentally handicapped men and women are capable of setting personal goals and communicating their desires and aspirations. Even nonverbal developmentally handicapped children and profoundly handicapped adults can often participate in decision-making and goal-setting if they are given a legitimate opportunity to do so.

CHAPTER I SPONSORSHIP AND OPERATIONAL RESPONSIBILITY

At present, the primary providers of Ontario's community-based residential services for the developmentally handicapped are local Associations for the Mentally Retarded (AMR). A small number of other charitable corporations also provide such services. In addition, some private operators provide residential care, mostly to children, in a variety of funding arrangements under the direct or indirect auspices of the Ministry of Community and Social Services or the Ministry of Health.

The Five Year Plan for services for the developmentally handicapped proposes significant expansion of community residential care and continued depopulation of the provincial Facilities. This factor, coupled with consumers' and parents' demands for more individualized approaches to service delivery, and private operators' expressed interest in obtaining funding for residential services for the developmentally handicapped have combined to raise questions about present sponsorship arrangements.

ISSUES

These questions are, quite simply:

1. Is the present mix of sponsorship the one that is most likely to facilitate the development of residential-care options for the developmentally handicapped?
2. Should the MCSS fund other kinds of sponsors or operators for community residential services?

BACKGROUND

The majority of the province's 3500 community residential spaces accommodate mildly and moderately handicapped adults and children. The limited capacity of these programs to serve more seriously handicapped individuals, particularly those with behavioral problems and other compounding difficulties, is a real constraint in the continued development of services for clients discharged from provincial Facilities. As well, community residential services must meet the pressing needs of hard-to-serve individuals who are at risk of institutional placement.

Pressure on the residential-service network also comes from the mental retardation movement itself. Over the last decade, many AMRs, especially in the major cities, have been transformed from organizations of parents, lobbying for education and sheltered workshops for their children, to large, service-providing agencies led and staffed by highly specialized professionals. As they have expanded direct-service delivery, some people have voiced concern over a perceived decrease in accountability to consumers, over bureaucratic tendencies, and over a program-oriented rather than an individualized approach to clients' needs. In addition, the emergence of People First, a self-help movement of developmentally handicapped adults across North America advocating their rights as citizens, has contributed to the demand for a wider range of residential options with the flexibility to serve individual needs.

The Ontario government's preferred approach to human services has been to use the private sector as providers. MCSS has tended to favour nonprofit agencies over for-profit operators or corporations, particularly in the field of mental retardation because of the historical role of the parents' movement and local associations in creating pressure for community services. Most of the latter continue to view their mandate as the development of a network of community services in the local area.

Of the approximately 120 AMRs in Ontario, 112 operate one or more residences under The Homes for Retarded Persons Act or The Developmental Services Act. Twenty-five other community agencies, such as Christian Horizons, Kinsmen, and L'Arche, also operate residences. Private operators licensed under The Children's Residential Services Act, the Schedule I Facilities Approved Home Program, or the Ministry of Health's Homes for Special Care and Nursing Homes program make up the remainder of the providers of residential services. (Appendix 1 provides a profile of these sponsors.)

Since the mid-1970s, MCSS has encouraged general as well as specialized community agencies to provide services for the developmentally handicapped. In fact, this policy of using generalized services was a cornerstone of the Ministry's expansion of community living opportunities and support to families with handicapped children. The goal was the social integration of clients, with an individualized, developmental, and normalizing focus.

As developmentally handicapped individuals have moved into communities, many agencies have indeed become more aware of their needs and have sponsored such support programs as Family Support Workers and Adult Protective Service Workers. One of the challenges over the next decade will be to achieve the appropriate mix of specialized and generic sponsorship.

AUSPICES FOR RESIDENTIAL SERVICES

A brief survey of present and possible auspices for the operation of community services may clarify some of the problems and the options.

Charitable Corporations

The predominant charitable sponsors for residential services are local AMRs, along with 25 other community agencies and a number of Children's Mental Health Centres. The potential for expanding this type of sponsorship lies in:

1. Existing organizations increasing their services.
2. Existing specialized organizations (for example, the Canadian National Institute for the Blind, the John Howard Society, Cheshire Homes) beginning to serve the developmentally handicapped.
3. Independent board-operated groups (such as TELC, which specializes in communication-handicapped children, and Ceci Homes, which serves severely and profoundly retarded children) developing and multiplying.

Schedule I Facilities

Facility based Community Services

The provincial Facilities have not sponsored many community residences to date. One notable exception is the St. Lawrence Regional Centre's development, in 1978, of five group homes for severely retarded adults and children in the Cornwall-Brockville area, operated both by individual private operators and local AMRs. Another is Surrey Place Centre's development, in 1979, of two group homes for profoundly retarded children and adults, operated until recently by Extendicare Ltd.

Approved Home Program

Of the 27 Facilities, 13 operate an Approved Home Program under which the institution purchases residential services from private operators. The residents placed in the homes are carried on the books of the Facility, and their management and monitoring is the responsibility of its social work department. Three of the total of 67 homes are incorporated as profit-making businesses, 6 are nonprofit organizations, and the remaining 58 are not incorporated.

Ministry of Municipal Affairs and Housing

In 1981, the Ontario Housing Corporation extended eligibility for assisted rental housing to developmentally handicapped adults who are single with no dependents. The policy statement issued at the time indicated that OHC's role is to meet a defined housing need rather than to provide social support services. (For tenants who are developmentally handicapped, support is provided by Adult Protective Service Workers and local AMRs according to guidelines worked out with the MCSS and the Ontario Association for the Mentally Retarded.) At the present time, approximately 65 developmentally handicapped individuals reside in OHC housing units under this joint Housing - MCSS program.

Municipal Governments

Municipal governments could sponsor residential services for the developmentally handicapped, but the likelihood must be regarded as very limited. Municipalities generally see the funding of such specialized services as a provincial responsibility and the operation of community residential services as the business of the voluntary sector in cooperation with the province. The transfer of the Family Benefits program to municipalities seems to have reinforced this view because the disabled caseload remained on the provincial social assistance program.

Some municipalities have sought to go beyond their regulatory powers regarding fire, health, and safety and asked for increased involvement with group home sponsors in matters of programming and staffing (see Chapter II). Their concern, however, pertains not to taking over responsibility for group homes but to the adequacy of monitoring them, particularly those run by for-profit operators.

Municipalities do provide accommodations for some developmentally handicapped adults in the sense that a small number are housed in municipally owned or subsidized hostels and units in nonprofit housing corporations. In both instances, however, the individuals are able to live relatively independently and are thus largely outside the client group for residential services for the developmentally handicapped.

Private Operators Funded by the Ministry of Community and Social Services

Children comprise the largest group of developmentally handicapped clients for whom the MCSS has been funding residential and foster-care services. These services are provided by private operators -either individuals who offer a few places, often in their own homes, or larger enterprises, which serve 10 to 40 individuals in a semiinstitutional setting that may be part of a chain. The purchases of services are made privately or by Children's Aid Societies or Probation or Aftercare authorities, on a per-diem basis or with "hard-to-serve" funding arrangements.

Few private operators provide residential programs for adults; however, neither has the MCSS encouraged entrepreneurs to enter the field. Financial incentives are nil; when the developmentally handicapped reach age 18, most go on Family Benefits or General Welfare Assistance - and those rates are too low to permit a private operator to provide support beyond room and board.

Private Operators Funded by Ministry of Health

During the past decades, the Ministry of Health has fostered more involvement of the private, for-profit sector in providing residential care to children and elderly and psychiatric aftercare patients. These include almost 3000 clients in nursing homes who are developmentally handicapped, and there has been concern over program standards and quality of care.

Because of the nature of the funding and enabling legislation for these programs, it has not been possible for developmentally handicapped individuals in them to have access to developmental programming. The per diems paid to operators have covered custodial and basic nursing care, and only limited monitoring of standards was provided. (Significantly, the program remained outside the mainstream of the 1970s' mental retardation movement with its commitment to normalization and developmental services.) The Tri-Ministry Project on Homes for Special Care and Nursing Homes was established in 1980 to provide assessments and developmental programming intended to bring the homes up to the service levels established in MCSS-funded residential programs.

THE PROS AND CONS OF VARIOUS AUSPICES

Each type of auspices for community residential programs has advantages and disadvantages, which deserve close examination in determining options for the future.

Charitable Corporations as Sponsors

Charitable organizations vary so much in their size and nature that generalizations are difficult to make. Some characteristics are, however, common to the majority and constitute advantages for sponsoring residential programs.

For example, the existence of a community board formally establishes the organization's accountability to the public for using government funds. Most agencies also recognize accountability to clients and their families, fostering opportunities for parental and volunteer input to programming. The traditional motivation for the development of services has been concern over quality, availability, and accessibility, and over the years the AMRs have articulated a service philosophy that incorporates widely accepted values and principles.

Furthermore, property owned by voluntary agencies is likely to remain in a human-services use, thereby ensuring continued public benefits from equity built up with public funds.

Nevertheless, the Ministry's near-exclusive reliance on charitable organizations, particularly the AMRs, has some disadvantages. The expansion of services has already placed severe pressures on the administrative and managerial capabilities of many agencies. Meanwhile, some areas of the province simply do not have enough charitable organizations prepared to provide residential services, particularly for hard-to-serve clients. In addition, smaller organizations do not have professional resources to assist in program development and to provide back-up to a group home. To alleviate the problem of a shortage of sponsors the Ministry could increase efforts to encourage the establishment of residential services by smaller and/or more diversified community organizations. This would include generalized agencies (service clubs, YM - YW - YMHAs), organizations already providing services to other client groups (CNIB, John Howard Society), and local special interest groups.

Schedule II Facilities as Sponsors

Schedule II Facilities could initiate small satellite operations, on their own or as joint arrangements with other service providers in the community (perhaps including for-profit operators).

Such Facility sponsorship would have a number of advantages. First, it could be an effective strategy for phasing down the institutions, offering a way to redeploy staff and resources; the expertise of staff could be especially useful in areas of the province that are presently underserved. Moreover, the availability of Facility resources would more or less assure rapid expansion of community group homes. It might, however, result in the transfer of institutional routines and practices (although this problem would diminish over time).

The Ministry of Municipal Affairs and Housing as A Service Provider

The Ministry of Municipal Affairs and Housing could increase its involvement in the provision of residential services to the developmentally handicapped in a variety of ways. OHC units for low-income adults are one such way; the rent-supplement program is another. These programs are, however, in extremely high demand and their potential for expansion may be quite limited.

In the future, however, the rent-supplement program may offer some very real possibilities if local agencies can locate landlords who are interested in the guaranteed rents provided by the program. These rent-supplement units would be more desirable than OHC housing, whose bachelor and one bedroom apartments which are the right size for individual developmentally handicapped people, are very often located in elderly persons housing development and thus not entirely appropriate. Moreover, the waiting lists for OHC housing are lengthy in nearly all areas of the province. Access to the rent-supplement housing units would reduce the pressure on large AMRs to expand their purely property management functions and working within a generalized program would further the goal of integration. Local agencies may well find the rent-supplement program available through their local Housing Corporation a useful option for some persons.

Service Provision by For-Profit Operators and Corporations

A move to encourage for-profit operators and corporations to provide community residential services to children and adults would have a number of advantages and disadvantages, both operational and philosophical. It would probably speed the expansion of community residences, and areas underserved by charitable organizations could be guaranteed the establishment of homes. Established management and administrative structures might increase cost effectiveness. And where private operators have demonstrated excellence in serving children, permitting them to expand could be in the best interests of young clients.

Some of the major concerns involve community reaction. In numerous public hearings, ratepayers' association meetings, and planning board and town council meetings throughout the province, the Provincial Group Homes Coordinator has encountered a widespread distrust of for-profit operators. This attitude, also reflected in a 1980 MCSS survey on acceptance of group homes, has several sources, including the perception that the operator is motivated only by the opportunity for monetary and real estate gains at the expense of clients and the public, and unease over the private operator's being able to use public funds without being accountable to a community board or elected officials.*

Whether the perception of private operators as always inclined to cut corners is correct, the MCSS may have difficulty monitoring them adequately. This was the experience of the Cornwall Project, which discontinued arrangements with one for-profit operator because of deteriorating standards and was dissatisfied with the other for-profit management of the homes it was sponsoring. Also to be taken into account in any increase of the use of for-profit operators is the response from charitable organizations now providing services, including the OAMR and the local AMRs.

Aside from very small scale operations of the approved home type, any involvement of for-profit operators should be through a local non-profit community board which may choose to contract out a service to a for-profit operator. MCSS will not generally enter into agreements directly with for-profit operators. If a for-profit operator is perceived by a non-profit board as providing the most reasonable option for service delivery, the expectations of that operation in terms of service quality and value for funds expended will be identical to those for other programs.

SUMMARY OF OPTIONS

Thus, the Ministry seems to have four options for providing an increased number and range of residential services for the developmentally handicapped:

1. Continue with the present policy of funding charitable organizations under The Homes for Retarded Persons Act and The Developmental Services Act, assuming that the primary providers of residential services will be local AMRs and, to a lesser extent, other charitable corporations. The present practice of excluding for-profit enterprises from direct sponsorship of residential services for developmentally handicapped adults would be maintained.

2. Provide resources for Schedule II Facilities to establish community programs to increase their capacity to place residents.

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* **Some municipal by-laws even stipulate that group homes must be nonprofit. Others, such as North York's and East York's require the operator to live in the home, thus eliminating multiple-unit profit-making operations.**

3. Explore strategies with the Ministry of Municipal Affairs and Housing for provincial housing programs to serve clients. These could include demonstration projects using MCSS funding for program support in assisted-housing units.

4. Amplify the other options by permitting the provision of service by selected for-profit operators at the discretion of non-profit boards. Permission could be given on a case-by-case basis by the Area Manager in consultation with the local municipality.

The Ministry should exercise considerable caution if any large entrepreneurs wish to develop services for the mentally retarded. Such projects should be subject to careful controls and guidelines developed after detailed consideration of the profit-making component of the operation. Monitoring of program, staffing patterns, and staff qualifications should be a high priority, particularly until the MCSS develops standards and guidelines for adult residences for the developmentally handicapped.

CONCLUSION AND RECOMMENDATIONS

It may be necessary for the Ministry to fund for-profit operators for the provision of community residential services for the developmentally handicapped in order to expand sufficiently the number and range of sponsors. However, serious concerns have been raised against such a move.

Given these conditions, the following is recommended:

1. *The Ministry of Community and Social Services should continue to rely primarily on non-profit agencies to provide residential services. It should encourage establishment of group homes by a range of community agencies, including generalized and special-interest agencies, as well as those focused on special client groups.*
2. *Schedule II Facilities should be able to redeploy some of their resources so as to establish community programs.*
3. *The MCSS and local agencies should explore options with the Ministry of Municipal Affairs and Housing and local Housing Corporations to expand their role in the provision of the shelter component of residential services.*
4. *The MCSS should only permit for-profit operators to obtain funding for group homes under clearly specified conditions with very careful controls and monitoring and with clear accountability to a non-profit community board.*

CHAPTER II ZONING AND COMMUNITY ACCEPTANCE

Public acceptance of handicapped people and their right to live in the community is essential to the continued effort to provide residential services for them outside large institutions. Zoning by-laws that recognize this right are the base for integrating the developmentally handicapped into communities throughout the province and depopulating provincial Facilities. In return, the Ministry of Community and Social Services must answer the concerns of municipalities and of group homes' neighbors.

ISSUES

Although the public is gradually accepting the principle that handicapped people should be able to live in their own communities, further progress is essential. The outstanding issues include:

1. Too many municipalities still use restrictive by-laws to hinder the expansion of community residence programs.
2. Municipalities that permit group homes need to be sure the ministries concerned will monitor them adequately.
3. Concentrations of group homes occur in municipalities with permissive by-laws, creating a "flooding" effect.
4. Private entrepreneurs are viewed as less desirable sponsors of homes than are charitable agencies.
5. The belief that the presence of a group home reduces neighbors' property values is widespread.
6. Many communities want provincial restrictions on the size of group homes.

BACKGROUND

Ontario municipalities vary widely in their willingness to accept group homes. Some prevent such residences by applying zoning by-laws that were written before the development of the group-home concept for people with special needs. In others, stringent requirements concerning density, lot size, and the like so severely limit the number of potential sites for group homes as to constitute a virtual prohibition.

Such by-laws, deliberately preventive or merely outmoded, impose considerable cost and uncertainty on would-be providers of service, who must seek site-specific amendments (spot rezoning) for any planned group homes. The process can be lengthy. The applicant must usually present the plans to a public hearing. If council then fails to grant the amendment, the applicant can appeal to the Ontario Municipal Board, which means further public hearings. A negative decision there can be appealed to Cabinet and the courts, a process that can require up to two years. Clearly, such procedures can tax the limited resources of a voluntary agency and may deter potential providers from considering group-home proposals.

In addition, zoning problems have led to the concentration of group homes in the limited number of areas where by-laws and housing prices make establishing them easier. The result - a large number of people with special needs living in one area - reduces a community's ability to provide a supportive atmosphere and places unfair responsibilities on it.

Group-Homes Policy: History

In 1978 the provincial government introduced a policy of encouraging but not requiring municipalities to permit group homes in all residential areas. The Secretariat for Social Development, designated as the lead ministry in implementation of the policy, established the office of Provincial Group Homes Coordinator to work with municipalities in designing and developing their group-home policies. Its guidelines, included in an information package distributed to all municipalities, recommend that municipal group-home policies (1) provide a definition for group homes; (2) establish group homes as a permitted use in all residential designations; (3) prevent undue concentration by requiring reasonable distances between facilities (or some other device to the same end); (4) provide for the continuation of any existing group homes not meeting the requirements of the zoning by-laws; and (5) provide for the municipal registration of group homes.

Present Status of Group-Homes Policy

Of Ontario's approximately 800 municipalities, approximately 130, containing 77 per cent of the population, have considered or are considering group-home policies. Of these, municipalities representing 48 per cent of the population have established group-home policies that are either completely open ended or have only minor restrictions on homes for developmentally handicapped people, and municipalities representing 18 per cent of the population are considering such policies. But 49 municipalities, representing 11 per cent of the population, have decided to retain the spot-rezoning process.

The remaining 670 municipalities have not yet considered group-home policies. For the most part, these jurisdictions are very small (587 have populations under 500), but collectively they represent 23 per cent of the population. These areas either require site-specific amendments or have no by-laws and, therefore, do not prevent group homes.

Appendix 2 details municipalities' actions on group-homes policy.

Monitoring and Setting Standards for Group Homes

The Ministry of Community and Social Services must take considerable responsibility for working with municipalities to ensure acceptable operation of existing group homes and geographically desirable development of new ones.*

In urging municipalities to adopt its recommended group-home policy, the provincial government indicated to them that, in return, it would take steps to ensure that any prospective operator would: (1) notify the municipality of his or her intent to establish a group home; (2) comply with zoning by-laws; (3) demonstrate a need for the program in the specific location; (4) demonstrate a knowledge of the community and a desire to seek community acceptance; and (5) comply with local health, safety, and fire regulations.

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* Although three ministries currently operate group homes (see Appendix 3), the MCSS's relationship with the municipalities will be particularly important in the coming years. First, projections suggest that future expansion of group homes will occur largely in the mental retardation field. Furthermore, the Secretariat for Social Development recently suggested transferring to the ministries involved the responsibility for implementing provincial group-home policy.

In addition, the province would also ensure that the relevant ministry would: (1) review the home's management and operations annually; and (2) require the operator to demonstrate continued compliance with local health, fire, safety, and building regulations. Steps have been taken to involve municipalities in the approval process; compliance with local by-laws for zoning, health, fire, safety, and occupancy levels is a requirement for establishing a group home, and municipalities have authority to register group homes and establish distance separation standards. However, some areas continue to require licensing controls outside their current jurisdiction in return for passing a permissive by-law. In response, the province has agreed to set up advisory monitoring committees with representatives from group homes, rate-payers groups, agencies, aldermen, and so on.

Cooperation between MCSS and municipalities in the ongoing monitoring of group homes, however, has not yet been fully established in all areas. For example, there is some lack of clarity over the responsibility for ensuring continued compliance with fire, health, and safety regulations. Municipalities grant initial approval based on a residence's fire, health, and safety provisions, but they do not routinely inspect for continued compliance with the regulations. Yet MCSS program supervisors do not necessarily review for these regulations in adult homes. (The Children's Residential Services Act now requires them to do so in children's homes.)

Another issue is the lack of standards and guidelines. Creating uniform standards and guidelines tied into funding agreements for residences for the developmentally handicapped, would be a useful step in promoting good relationships with municipalities.

Concentration of Group Homes

In encouraging municipalities to pass by-laws permitting group homes in residential areas, the Secretariat for Social Development suggests the use of distance-separation standards to prevent overconcentration in any particular neighborhood. This tack has allayed some local fears, but municipalities considering permissive by-laws still fear they will be "flooded" with group homes.

The issue is a difficult one whose resolution clearly depends on the hope that the municipalities that have not yet decided on group-home policies will adopt nonrestrictive ones and that there will be an eventual change on the part of the seven cities with populations exceeding 50,000 that have chosen to retain spot rezoning.

Some agencies, including the Ontario Association for the Mentally Retarded, have urged the government to amend The Planning Act to require municipalities to permit group homes, thereby leading to a fairer distribution of homes across the province. However, the government policy remains one of suasion only, in the belief that an approach based on cooperation and public education will achieve better long-term results.

Sponsorship and Qualifications of Operators

Communities throughout the province have expressed a preference for group homes sponsored by charitable corporations over for-profit operations, and some municipalities have responded to this public concern by excluding profit-making enterprises through their zoning by-laws. At issue are questions of quality of care, the qualifications of operator and staff, and private entrepreneurs' lack of public accountability. Chapter I discusses these issues in detail.

Group Homes' Effect on Property Values

A traditional concern of homeowners is that the presence of a group home in a neighborhood depresses its property values. Research suggests little evidence to confirm the belief. However, the MCSS and operators must carefully consider and address this and other concerns in areas where group homes are located or proposed.

One strategy is to establish residences in nonresidential areas; it avoids concerns but violates the principle of normalization by isolating clients from a residential community. Another approach is for a home to move in anonymously, like other families. The literature is not conclusive on the relative success of low- and high-profile strategies. In some cases, an informed community readily lends its support to integrating the home and its residents; in other cases, advance attempts to smooth the way have led to increased resistance.

In the long run, only public education on the importance and merits of group homes can counteract negative public attitudes. The Secretariat for Social Development is currently conducting an information campaign aimed at increasing public awareness and acceptance of group homes.

Kinds of Clients and Size of Homes

The group-home policies of a number of municipalities reflect community concerns by excluding certain types of residents, such as people who have been in conflict with the law (see Appendix 2). Very few municipalities have expressed specific concern over the developmentally handicapped, although there appears to be some resistance to severely retarded clients in some areas. On the whole, however, acceptance of this client group appears to be good in comparison to some others.

Many municipalities are also concerned over the possible size of group homes. The provincial policy sets group-home size as three to ten persons exclusive of staff, but some municipalities have said they would prefer the maximum to be smaller than ten and to include staff.

RECOMMENDATIONS

1. *The Ministry is identifying those communities where scheduled depopulation of provincial facilities will require expansion of residential services during the next five years and is targeting these municipalities for educational work preparatory to group-home development. This will involve obtaining information on the identified municipalities, including the present status of their by-laws, enforcement of regulations, and concerns regarding provincial group-homes policy. The Ministry should designate an individual in each area to work with Program Supervisors, Facilities staff, prospective service providers, and municipal planners and politicians. The Ministry's role would be to facilitate municipal cooperation with provincial group-homes policy and to provide information about its objectives, standards, and need for group homes for developmentally handicapped persons.*

2. *The Ministry of Community and Social Services should undertake, as rapidly as possible, the development of standards and guidelines for adult residences for the developmentally handicapped. These standards and guidelines should cover areas of concern to municipalites, including program quality and staffing qualifications. A standard similar to that in the Childrens' Residential Standards should require a would-be operator to prepare a plan for securing neighborhood acceptance of the residence.*

CHAPTER III ADMISSION AND DISCHARGE PROCEDURES

Each year about 1000 persons, 360 children and 700 adults, are admitted to long-term care in residential programs for the developmentally handicapped funded by the Ministry of Community and Social Services.* These programs may be community based or may be those of the large provincial Facilities. At present, responsibility for decision-making on placement rests, for the most part, with individual administrators of Facilities, community residence directors, professional staff, and parents, although there have been (and continue to be) several attempts to coordinate admissions in various regions of the province.

The implementation of the Ministry's Five Year Plan for services for the developmentally handicapped will require stronger regional management of residential services to achieve Facility depopulation targets. Closer screening of admissions to community group homes than occurs at present may be necessary to permit access for Facility residents and hard-to-serve clients (who would otherwise create pressure on institutional services). This would need to be done in conjunction with the providers of residential services.

ISSUES

Admission and discharge procedures in residential services raise the following issues:

1. Are community-based residential programs fulfilling their mandate with respect to admissions?
2. Are children and adults with mild and moderate developmental handicaps being placed in intensive residential programs without sufficient attempts to secure less restrictive alternatives?
3. How can we improve the coordination of placements in and movement through community residential programs?

BACKGROUND

The Facilities and the "50/50 Rule"

To assist in depopulating the Facilities by ensuring that their residents have equal access to community beds, the Ministry of Community and Social Services has promoted a policy requiring operators of community residences to take half their residents from the Facilities. This "50/50 rule" has never been put into written policy form and it has been subject to various interpretations.

Statistics are not available on adult residences, but MCSS staff report that the rule is not strictly adhered to. A recent survey of children's residential programs found that the majority do not admit half their clients from the Facilities. The reasons given by respondents echo those given to Ministry staff who deal with adult programs, including:

1. Vagueness of the 50/50 policy. It leaves unclear the definition of "a Facility admission." (For example, does it include a child whose case is managed by Surrey Place Centre? A person placed in a Facility for short-term admission? For parent relief?) In addition, does the policy apply to vacancies in existing residences or only to new beds?

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* "Admissions" may be of persons entering care for the first time or of persons moving from one program to another.

2. Pressure from community families, which can be so great that residences find it virtually impossible to refuse places to local children and adults.
3. The reluctance of some community programs to accept certain clients from Facilities because of severe behavior problems.
4. The claims of some community residences that there are not enough Facility clients who meet their admission criteria or who originate from the local catchment area. On the other hand, Facilities say that some community programs are too restrictive in their admission policies.

Screening and Other Committees

Various initiatives have been undertaken in recent years to deal with problems of long-term residential placement.

Screening Committees

Discharge Liaison Committee (Central Region). The District Working Group originally established this committee in 1976 to provide a central intake point for all Schedule I Facilities' referrals to community residential programs in Metropolitan Toronto. Representatives of the Facilities, community agencies, and the Ministry were to have authority to make decisions on individual placements. However, issues of confidentiality and practicality together with a need for basic liaison work and crisis management, prevented the group from fulfilling its original mandate, and it soon changed its focus to establishing standardized procedures and forms for admission to programs.

Children's Residential Screening Committee (Hamilton-Wentworth). This committee was initially concerned only with foster care, but it is gradually expanding its function to screening referrals to all residential services for developmentally handicapped children in the area. The group operates by consensus and is not formally empowered to make decisions about placement. It reviews approximately four cases per month and makes recommendations to residences, including the local Schedule II Facility, and to parents regarding admission and alternative support services.

The Committee for Hard-to-Serve Mentally Retarded Persons (Bruce/Grey and Waterloo/Wellington MR Working Groups). This recently established committee reviews cases of hard-to-serve children and adults to determine placement and/or service packages. Although there are no present plans to broaden its mandate, it could evolve in the future.

Proposed Third-Party Review for Children Admitted to Residential Care

The Ministry is proposing that The Children's Services Act make mandatory certain procedural safeguards for children admitted to long-term residential care because of two major concerns: (1) institutionalization entails risks to the child; and (2) the danger of inappropriate commitment.

The Ministry's "Consultation Paper: Omnibus Legislation: The Children's Services Act" recommends that an independent placement-review body be granted authority to make decisions regarding a child's admission to, discharge from, or transfer within residential care and that it be required to conduct informal preadmission hearings: (1) for all admissions to institutions; (2) for all admissions of children six years of age and under; and (3) whenever a child twelve years of age and over does not consent to admission.

PROPOSAL

Given the complexity of the issues and the lack of time-tested models, it is proposed that the Ministry develop pilot projects to test and evaluate admissions and discharge committees in residential services for the developmentally handicapped. These committees would operate on the basis of voluntary co-operation. Participating agencies would retain the ultimate decision making authority. The premise is that the bringing together of a number of persons with knowledge and expertise will enable them to perceive residential needs and resources in a wider context than that of their own agency. The committees would seek both a consensus regarding the appropriate residential services for individuals and a rational utilization of the available community resources.

The general goals of such committees would include:

1. Rationalizing the process of determining a residential placement or alternative according to individual needs.
2. Providing a workable instrument to implement the 50/50 strategy for depopulating the Facilities. (See Appendix 4 for one proposal.)
3. Creating links between the Facilities and community agencies.

A number of options exist for their mandate, scope, authority, membership, and relationship with existing planning/review bodies.

The Ministry could provide guidelines for the groups' broad functioning, but it should be up to each area or region to establish one or more committees appropriate to local conditions and priorities. Each committee would act as a single point of intake with authority to review all referrals to long-term residential placement of the developmentally handicapped within a geographic area and to recommend appropriate programs or alternative services. Since such committees would rely on voluntary cooperation among service-providing agencies, they would have to adapt to local priorities. They would also require time to establish credibility in the community and expertise in carrying out the process of matching individual needs to programs.

Such a joint planning process focused on individual clients would of course, be administratively difficult. Hence, the need to test such committees in three or four areas of the province. One central issue to be resolved by experience is whether the committees should at some future dates have power to compel or prevent admission to a residence, including a Facility.

In addition, pilot projects could work out the many procedural questions, such as: (1) on what geographical base (region, area, district, or other), should committees be developed? (2) which admissions (emergencies, parent relief, assessment, less than 60 days), should be excluded from the Committee's purview? (3) what standardized procedures would obtain information on the client's residential needs that would be acceptable to the referring and receiving agencies? and (4) could membership on a committee be mandatory for all funded programs even if it only made recommendations?

RECOMMENDATIONS

1. *The Ministry of Community and Social Services should clarify in writing the 50/50 rule requiring community residences to accept Facility residents. It should then monitor the policy more closely with service-providing agencies.*
2. *The Ministry should establish pilot projects to test the operation of admission and discharge committees for residential placement of developmentally handicapped individuals along the lines suggested in this paper.*

CHAPTER IV EVALUATION OF RESIDENTIAL SERVICES

Several chapters of this paper have already noted the need for effective evaluation of residential programs funded by the Ministry of Community and Social Services. The purpose is to enable recommendations to be made and to provide follow-up consultation that will assist programs to move gradually toward the attainment of their goals. A complete evaluation includes:

1. Examination of adherence to basic principles of service delivery.
2. Review of the effectiveness of operations, including management and staffing practices, use of financial and material resources, use of staff, and so on.
3. Review of program quality that examines adherence to professional and program standards of service delivery.
4. Assessment of the program's success in setting and meeting goals - in other words, a review of outcome.
5. Measurement of cost-effectiveness and efficiency.

ISSUES

1. What are the prerequisites of an effective and complete evaluation?
2. What kinds of evaluation should be done:
   (a) Examinations of adherence to program principles?
   (b) Operational reviews?
   (c) Program reviews?
   (d) Outcome reviews?
3. When and by whom should such evaluations be done?
4. What additional operational and program standards will be required?
5. Should standardized instruments be adopted for each type of evaluation?

BACKGROUND

Over the last six years, the number of adults' and childrens' residential programs in Ontario has more than doubled to approximately 3,000 and 400 respectively. MCSS Area Offices regularly review certain aspects of their operations, usually in connection with the budget process, and have undertaken more extensive reviews under special circumstances. The instruments used for these more extensive reviews varied in specifics, but showed considerable agreement on the areas to be covered. The need to put in place a more regular process for program reviews has been recognized, and the expansion of the last half decade or so has underlined the urgency of this need. Some steps in this direction are already being taken by the Operational Review and Audit Branch of the Ministry which is reviewing the operation of 15 local Associations for the Mentally Retarded in 1983.

DISCUSSION OF ISSUES

Prerequisites for Effective Evaluation

Adequately documented policies and procedures are essential to evaluation because they provide the framework for measuring the achievement of goals, for comparing what is happening with what is supposed to be happening, and thereby identifying problem areas. In many cases, the first goal of an evaluator must be to determine if these prerequisites exist and, if they do not, how they can be developed most easily.

For a thorough evaluation of a residential program, these prerequisites include:

1. A clear and explicit statement of the principles underlying the program.
2. A clear statement of the program's specific objectives. The evaluator must decide if the goals for the individual, the activity, and the program are expressed in ways that can be measured.
3. Adequate data available for analysis. Some residential programs have quite inadequate records, owing to the tendency to resist "unnecessary paperwork." When basic data are lacking, the evaluator must decide whether to proceed on the basis of such information as can be gleaned from interviews or to postpone the evaluation until proper documentation has been done.

Types of Evaluation

The definition of evaluation suggests four different kinds of reviews, in addition to an examination of cost-effectiveness. In practice, the four may overlap, but it is conceptually easier to list the components of each separately.

Much of what would be appropriate for one model would not necessarily be useful for all. For example, operational reviews and a number of the topics covered under program review have little relevance for alternative or specialized family care and even less for the parental-home model. However, certain aspects of program and outcome reviews are relevant for all residential models. So are examinations of philosophical bases, which program reviews tend to reveal by looking at the activities and interactions that go on in residence.

I. Reviews of Adherence to Principles of Service Delivery

The circumstances under which one lives have a significant influence on all aspects of a person's life. In order to protect the consumer of services, it is necessary to measure the adherence of programs to principles of service delivery that try to ensure this influence is beneficial. One such set of principles is listed in the Introduction to this paper. Much of what these principles contain can be summed up by the term "normalization," which, although it has been somewhat misused, incorporates practices that are both effective as techniques and desirable as goals and that have been operationally defined in a variety of instruments and endorsed in a number of MCSS documents.

II. Operational Reviews

An operational review of a residence should usually cover at least the following:

1. Adequacy of record keeping.
2. Role and function of the board of directors.
3. Budgeting and management of financial resources.
4. Personnel procedures, including staff development.
5. Organizational structure.
6. Safety procedures.

III. Program Reviews

A review of a residential program should usually examine at least the following factors:

1. Criteria and processes for admission.
2. Adequacy, timeliness, and relevance of assessments.
3. Quality of individual program plans.
4. Adherence to accepted practices of implementing individual programs.
5. Procedures for coordinating services.
6. Placement procedures.
7. Model coherency.
8. Clients' contributions to individual and residential plans.
9. Means of responding to clients' grievances.
10. The physical and social environment.
11. Participation in day programs.
12. Use of general community services.

IV. Outcome Reviews

An outcome review of a residence should usually examine at least the following factors:

1. Clients' movement toward independent living.
2. Clients' acquisition of skills such as fine and gross motor, self-care, domestic, social and interpersonal, community and recreational.
3. Level of clients' satisfaction.
4. Achievement of goals set out in individual program plans.

These indices provide a basis for determining overall effectiveness, but this overall determination becomes more useful if it can be linked to specific variables open to change.

When Should Such Reviews Be Made? By Whom?

The questions of how often and by whom evaluations should be carried out are best answered by considering internal and external reviews separately and subdividing the latter into regular and special circumstances.

For all kinds of external reviews, evaluators can be taken, with advantage, from four groups: MCSS staff, particularly the Area Program Consultant; private and in-house consultants; peer evaluators drawn from the staff (including family-care operators and parents) or boards of similar programs; and consumers. Table 1 lists the strengths and weaknesses of each type. One way of making the best use of each kind of evaluator is to assemble a team consisting of a representative from each group so that various interests and types of expertise are represented. The work can be coordinated by the consultant, who collects and distributes data, writes the report, and generally coaches his or her fellow team members on the evaluation process.

The suggestion that clients be included in all kinds of evaluations is worth noting. Recent professional literature and government documents have emphasized the involvement of consumers in influencing the programs that serve them. One of the areas in which their impact can be greatest is that of program evaluation, particularly if the instruments to measure client satisfaction are adequately developed. Although the areas in which client views can be elicited and the means for doing so will vary widely, even the most severely handicapped persons can express feelings, preferences, or desires regarding some of the major aspects of their residential life.

TABLE 1 STRENGTHS AND WEAKNESSES OF POSSIBLE EVALUATORS

Evaluators	Strengths	Weaknesses
Ministry staff	Clear reference to funding guidelines	Generic consultant not rehab specialist
	De facto Ministry approval of recommendations	Regulatory ("strong-arm") function of government may be overemphasized - lack of trust
	Availability of data on comparable programs	Possible investment in failure to implement recommendations
	Experience in content areas and functional areas	Possibly perceived as threatening because represent funding source
	Possible investment in implementation of evaluation	
Consultants	Objectivity since not part of residence sector	Possibly too generalized; application to residential program may require "translation"
	Skills in evaluation process (i.e. collection, synthesis, and analysis of information)	Possible avoidance of controversy in order to preserve relationship with client
	Experience in organizational consulting	No investment in implementation of evaluation
	Methodological expertise	
	Conflict-management skills	

Evaluators	Strengths	Weaknesses
Peers	Experience in operation of residences	Not trained in process of evaluation
	Familiar with language used by residence operators	Credibility contingent on personal background and experience
	Clear reference to policy and to precedent of the organizations	Possible compliance rather than "rocking the boat"
	Investment in implementation of evaluation	Possible lack of financial resources to implement
Consumers	Personal experience of services provided	Possible poor understanding of decision issues in organization management
	Access to the unexpurgated opinions of other consumers	Possible intimidation by the "professionals" involved in the evaluation
	Objectivity derived from detachment from service provision	Possible lack of investment in the outcomes of evaluation and follow-up
	Possibly a healthy dose of nonprofessional commonsense	Possible lack of objectivity

Internal Reviews. Any programs with a full-time staff should do an annual review of their adherence to the principles, their operational effectiveness, the quality of their program, and the outcome of the program. Such reviews will probably not be as extensive as external reviews but will provide information necessary for improving the quality, effectiveness, and efficiency of the program. Alternative and specialized family-care programs and parents caring for their handicapped children at home could also attempt annual self-reviews if appropriate instruments were available.

By definition, internal reviews are done by the residence's board members, staff, and clients with little or no outside participation.

Regular External Reviews. All residential programs should receive complete evaluations - reviews of adherence to principles and operational, program, and outcome reviews at least every four years. Such reviews can provide the information needed for a gradual improvement in the quality and effectiveness of the program and can stop any deterioration before it has progressed too far. Guidelines regarding the frequency of such reviews will need to be developed. One factor to be taken into account in determining the frequency clearly is program quality. A second may be size. Larger residences should perhaps be reviewed more frequently because the consequences of any program inadequacies affect more people. For example, even the smallest program should be reviewed at least at four-year intervals, and the largest (30 beds or more) every two years.

The inclusion of staff and/or board members on the evaluating team is important. Many of the problems of evaluation rise largely from the mistrust, misgivings, and misunderstanding of reluctant participants in a process over which they have little control. Most can be removed if the boards and staff take part in the evaluation and if the evaluators are sensitive to the unique features of each residence.

Requested External Reviews. If a residence is uncertain about the effectiveness of certain parts of its operation and wishes to obtain information to help it improve its program, it may ask one or more of the external review sources for a complete or partial evaluation. The evaluators for such a review should probably include an MCSS representative, a peer representative from a similar residential program, and a consumer or client.

Special External Reviews. An MCSS Area Office may require an external review of some or all aspects of a program any time serious questions are raised about it - by consumers or their advocates, by professional individuals or organizations, by MCSS staff - and a preliminary examination reveals that further review is merited. The evaluators should be the persons whose expertise is most relevant to the issues to be addressed but should probably include an MCSS representative, a representative from another residence, and a consumer.

Residential Standards and Guidelines

Evaluation demands standards. The regulations for The Children's Residential Services Act already incorporate a set of standards and guidelines for all types of children's residences. Evaluation of community residences may, however, require the development of supplementary standards and guidelines. Standards and guidelines for adult residences are also needed. Some standards specific to residential services for mentally handicapped adults have been worked on in the past. The Accreditation

Council on Mental Retardation and Developmental Disabilities also has a set of standards that has received widespread acceptance in the United States, and a number of Facilities have developed standards covering certain aspects of their operation for their own internal use.

It is essential to reach some agreement regarding the extent to which adults' and children's residences need different standards or guidelines, the nature and extent of any supplementary standards or guidelines that need to be promulgated for the developmentally handicapped, and the extent to which existing standards or guidelines can be adopted or modified for use in Ontario. Since the applicability of the standards or guidelines may vary from one model of residence to another, it may be that some of them will only apply to some types of residences. Moreover, standards and guidelines specific to certain types of residences may also need to be developed.

The instruments used in operational and program reviews are simply measurements of adherence to standards or guidelines. Therefore, agreement on the latter must preceed the construction of instruments. One problem with the instruments now in use is that an item often refers to a standard or guideline that is not explicit, so it is difficult to make an objective, reliable, and valid rating. In the absence of the anchor points provided by standards and guidelines as to what practice should be, judgments become purely subjective.

Should Standardized Instruments be Adopted for Ontario?

Any discussion of evaluations leads naturally to a consideration of an instrument for them. Each of the four types of reviews will demand its own instrument, and each of those may need several versions so that it can be applied to various residential models.

Measurement of Adherence to Principles. MCSS residential program reviews implicitly examine programs' adherence to principles of service delivery, but no common set of criteria is used. The Program Analysis of Service Systems (PASS), which focuses on normalization in human services, may be useful here. Since it is designed to be used for all types of human services, its ratings are, of necessity, very general; hence, an evaluator using it requires considerable judgment and extensive training to assign a rating in any particular situation. However, there are several simpler versions of PASS for residential evaluations and it should be possible to draw on them to develop a simple and direct measure of adherence to the basic principles. Such an instrument would eliminate the need for a team of raters, reduce the training period for the rater, and make the ratings more reliable and valid.

Operational and Program Reviews. Every group undertaking operational and program reviews of residential programs has developed its own evaluation outlines, and they all appear similar. It would probably be useful to combine them into a single standardized instrument that could be used by all groups, although some of its criteria, of course, would be only applicable to certain types of residential models.

It will also be necessary to develop or adapt an instrument specifically designed to measure the social and physical environment, since this aspect of program review has been relatively neglected.

Outcome Reviews. MCSS is already studying the rating scales and checklists that are available for use with the developmentally handicapped in order to suggest which ones would be most useful in a residential setting. In addition, an adequate measure of clients' satisfaction must be developed. Such an instrument can draw not only on existing scales, but also, to some extent, on the instruments that may be developed as a result of the current proposals in the workshop review.

RECOMMENDATIONS

1. *Residence operators, clients, and the Ministry of Community and Social Services should develop a set of principles as a philosophical basis for residential programs funded by MCSS.*

2. *Residences that have not yet done so should formulate, with the participation of clients:*
    - *(a) A set of general goals, with a statement of the the types of program and activities to be undertaken to achieve them.*
    - *(b) Specific program goals.*
    - *(c) Specific measurable goals and objectives for each client, to be included in the Individual Program Plan.*

3. *An assessment of the prerequisites to evaluation should precede each evaluation; where significant shortcomings are found, the evaluation should suggest ways to rectify them.*

4. *Although programs and operational reviews may, under special circumstances, examine selected aspects of a residential program in order to deal with specific issues, in general, both the annual internal reviews and the periodic external reviews should include:*
    - *(a) An examination of adherence to program principles.*
    - *(b) An operational review.*
    - *(c) A program review.*
    - *(d) An outcome review.*

    One or more of these components may, however, be omitted for a specific reason, for example, in cases of the developmentally handicapped living in alternative or specialized family-care homes.

5. *Residences should do an annual internal review of all those areas relevant to their particular programs.*

6. *Residences may request a complete or partial evaluation, either through the MCSS Area Office or directly from one or more of the possible types of participants, as appropriate to the kind of evaluation needed.*

7. *The MCSS Area Office may require a complete or partial external evaluation when special circumstances indicate that such an evaluation is merited.*

8. *An external review involving each of the four areas listed in Recommendation 4 should take place in each residence at least every four years. Specific guidelines regarding criteria for determining the frequency of evaluation need to be developed.*

9. *The annual internal review should be conducted primarily by staff, board members, and clients of the residence, although outside help can be obtained if desired.*

10. *Evaluations based on requests or under special circumstances should involve representatives of those groups that are appropriate to the task but should also probably include an MCSS representative, a residential representative, and a consumer or client.*

11. *The regular external evaluation (on average, every four years) should involve the three parties referred to in 10 above and should be coordinated by a consultant who is independent of any of the other parties.*

12. *Agreement needs to be reached regarding:*

    (a) *The extent to which different standards and guidelines are required for adults' and children's residences.*

    (b) *The nature and extent of any supplementary standards or guidelines that need to be promulgated for the developmentally handicapped.*

    (c) *The extent to which standards and guidelines specific to certain models of residences need to be developed.*

    (d) *The extent to which existing standards or guidelines can be adopted or modified for use in Ontario. Additional standards and guidelines should be developed as necessary.*

13. *Standardized instruments for the external reviews should be developed (building on existing instruments wherever possible) for evaluating adherence to principles and for doing operational, program, and outcome reviews. Several versions of the instruments may be necessary to ensure relevance to all residential models. Relevant persons and agencies including operators of residential programs, clients, and experts in evaluation, preferably of residences should have input into the development of standards and instruments. It will also be necessary to develop or adapt a means of measuring the physical and social environment of a residence. These instruments may also, of course, be used by programs in doing their own reviews.*

14. *Outcome reviews should examine all four indices of program effectiveness: clients' movement toward independent living, clients' acquisition of life skills, clients' satisfaction, and achievement of goals. In order to accomplish this, it will be necessary:*

    (a) *For residences to adopt an assessment system if they have not already done so. The IPP project is examining a large number of functional assessment instruments and will make recommendations, which residences may follow at their discretion.*

    (b) *To develop a means for measuring clients' satisfaction.*

CHAPTER V GENERAL MODELS OF RESIDENTIAL SERVICES

Given the purpose and principles of residential services for the developmentally handicapped and the wide range of type and severity of disability among these clients, it is clear that a number of models of service are needed to meet their residential needs adequately. This chapter will provide a set of general models. Later chapters will show how they can be adapted to meet various specific needs, both those of the less disabled, and those of the more severely disabled or "hard to serve".

ISSUE

What types of models can be developed to provide a full range of community residential services to Ontario's developmentally handicapped persons?

BACKGROUND

In General

Across North America, the last decade has seen a substantial reduction in the number of developmentally handicapped persons living in large institutions and a corresponding increase in the number in smaller community-based facilities. In the United States, the institutional population declined from 173,775 to 139,410 between 1972/3 and 1978/9, while the number of persons living in community accommodations increased from 8,000 to 62,397. The trend in Canada is similar.

Initially, most persons discharged from institutions were mildly and moderately handicapped, but more recently, increasing numbers of severely, profoundly, and multihandicapped individuals have been moving into community residential settings.

In Ontario

Since 1974, the population of Ontario's large Schedule I Facilities has declined from 7,259 to 5,694. Between April 1974 and March 1980, these institutions discharged some 2415 adults, of whom 2200 are currently still in some form of community setting. The largest proportion of those discharged - 40 per cent - went to live in community residences,* most of which are operated by local associations for the mentally retarded. In 1982/83, the operating budgets for these community programs was approximately $47 million.

Today, some 2400 borderline, mildly, and moderately retarded persons still remain in Schedule I and II Facilities, and since fewer than 700 of them have additional physical or behavioral handicaps, virtually all could be candidates for community living. Moreover, since it is now clear that quite seriously disabled persons thrive in community settings, efforts should also be made to return many of the Facilities'more severely and profoundly retarded to the community. At the same time, since long-term admissions, particularly of children, to the Schedule I and II Facilities are being reduced, new clients need community-based residential services.

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* About 23 per cent were transferred to a residential setting providing some form of nursing care, 18 per cent were discharged to live independently, and 18 per cent to live with their families.

INTRODUCTION TO GENERAL MODELS

Despite the very great variety of residents to be accommodated, service can be provided with seven general models. Discussion of them here includes consideration of four factors: the level of client need, the number of residents involved, staffing, and external support services needed. A fifth factor, the nature of the programs to be provided, will be discussed in later chapters.

The Level of Client Need

Client needs are the basis of all residential programs. Assessment of need requires accurate and relevant information on a resident's (or prospective resident's) abilities and disabilities in at least four areas: self-care, behavioral/emotional problems, medical and physical problems, and intellectual functioning.* With this information staff can assess the level of a particular client's residential need and hence the level of service required.

The gradations revealed by such a system will almost certainly be continuous. In presenting residential models, however, it is useful to discuss client need in terms of five categories: those of persons who are (1) somewhat independent, (2) somewhat dependent, (3) quite dependent, (4) very dependent, and (5) extremely dependent.

The Number of Residents Involved

The past 15 years have seen a substantial shift in residential programs for the developmentally handicapped from large institutions for 100 or more persons toward projects that serve 8 to 20 individuals. The latter programs were intended to provide a homelike atmosphere, to enable residents to be more a part of the community in which they lived, and to eliminate rigid institutional practices and routines, as well as to provide more individualized programming. Many small residences have achieved a number of these objectives, and most people working with the developmentally handicapped agree that, other things being equal, smaller is better.

Yet a residence of 8 to 20 beds is, in many ways, not really small or normal. A client in such a home shares his or her most intimate environment with 12 to 25 residents and staff; in the rest of the society, the number of persons sharing accommodation averages three to four. Smaller units (four beds or fewer) seem more likely to:

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* See Appendix 5 for a discussion of some of the advantages of this system and Appendix 6 for an example of an instrument that might be used to put it into effect. Such a system would not, of course, replace the detailed and extensive individual assessments required for the development and implementation of individual program plans as envisaged in the Individual Program Planning policy paper.

1. Encourage the development of the affective ties and intimacy that create a homelike setting and an improved quality of life.
2. Reduce the complexity of the social environment with which residents have to deal. Reducing the number of persons in a group from ten to five reduces the number of individuals and combinations of individuals with whom a person may have to deal from more than 1,000 to 26, a decrease of nearly fortyfold.
3. Develop a sense of personal responsibility, mutual support, and affection among both residents and staff. For the staff, these attitudes can provide the motivation essential to high-caliber services. They also reduce staff turnover, thereby providing greater security and stability to handicapped residents, who suffer fewer separations from intimate associations. And more stable, permanent staff members (including family-care providers) become more effective role models for residents.
4. Help staff become more effective motivators of residents. Stronger links of affection come with smaller numbers; so do more frequent interactions, which permit staff to understand better the needs, wishes, and desires of the residents.
5. Make possible the development of flexible, personalized practices and daily routines and the elimination of the routinized, block treatments inevitably required whenever large numbers of people live in close proximity.
6. Provide increased opportunities for the integration of residents into the recreational, commercial, religious, and social activities of the community.
7. Encourage more age- and culture-appropriate interactions between staff, residents, and their friends.
8. Make possible more consistency and hence greater effectiveness in programming. Large numbers of staff are certain to increase substantially the variability with which programs are implemented.
9. Create an environment that minimizes the range of maladaptive behavior, thus reducing the probability of the residents learning new maladaptive behavior.
10. Reduce community concerns about the presence of a group home.

Staffing

Different residential models require a variety of staffing arrangements, but, in general, a residence should be regarded as its residents' home. Whenever possible it should be the staff who move to a different location or reduce (increase) their input into a particular residence, while its residents remain in their home. This practice is not, of course, possible for those models in which services are provided in the caregivers' homes. Neither would it be possible in models designed for flow-through. A very large proportion of the individuals in residential care can, however, be placed in staffed settings that can become their permanent homes.

Day Programs and Support Services

All client needs cannot be met within a residential setting. For this reason, the general models assume the availability of various external supports. For example, all assume that all residents will be working or attending a day program (school, developmental center, workshop, life skills classes, and so on).

Models A, C, and D below may also require relief services. Depending on the needs of specific residents, any of the models may, from time to time, require external supports, such as nursing, physiotherapy, occupational therapy, as well as psychiatric, psychological, and behavior-management services. These services can be provided by professionals and/or paraprofessionals on a consulting and/or a direct-service basis. The number of hours of care these external-support workers are to provide should reflect the needs of the specific residents, as outlined in their individual program plans; a contract should be developed to tie services to these needs.

It is in this easily varied use of external supports that the general models gain flexibility. No model is tied to the continued use of experts; yet even the nonprofessional caregivers of Models A and C could manage clients with quite serious handicaps, given sufficient external support.

MODELS OF RESIDENTIAL CARE

The general models described here provide at least three, usually five or more options for persons at each level of disability.* All can be located in any type of residential quarters, including a detached or semidetached house, a townhouse, or a condominium or rental apartment. The use of side-by-side semidetached houses, with an internal connecting door should be considered for a program involving five or more residents.**

Model A: Living with One's Own Family

This model involves one handicapped person (less frequently two or possibly three) living with parents or occasionally with siblings, spouse, or other relatives. It is appropriate for developmentally handicapped persons at all levels, excluding perhaps although not necessarily, the extremely dependent.

The parental model is certainly regarded as appropriate for children, but some concern has been expressed regarding its appropriateness for adults. Rather than making such a blanket statement, it seems more reasonable to assess each case individually in terms of the preferences, skills, and needs of the parties involved, as well as the available alternatives and support systems.

Model B: Supported Independence

This model has one to four somewhat independent or somewhat dependent persons living together who are provided with for less than one to up to 5.0 hours of staff time per person per day from itinerant staff such as homemakers, attendants, behavior-management personnel, apartment support workers, and so on.

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* For some clients, one could add the option of completely independent living. Such a model is not described in this paper because a person living in such a setting requires no services related to residential care.

** Subject to municipal regulation.

Model C: Alternative Family Care

Also called foster care (or individualized placement in the case of adults), this model has one or two persons (3 persons with area office approval) placed in a private household that substitutes for their own families. It is suitable for persons who are somewhat independent or somewhat dependent and can also be made available to persons who are quite dependent if appropriate training is given the care-providers. Such homes would generally provide from 1 to about 3 hours of care or training per client per day. Residents attend day programs and emergency backup and other supports would be available to the sponsors, but other external supports should average less than one hour per day per client.

The addition of more support services would create a variant of this model, suitable for one or two quite or very dependent persons who require more intensive and/or skilled services than nonprofessionals are normally able to provide.

Model D: Specialized Family Care

In this model, one to three persons who are quite or very dependent live with a family in which one or both spouses have some professional training and experience in nursing, teaching, psychology, residential counselling, physiotherapy, occupational therapy, and so on.

Because of the needs of the residents, care in this model is more expensive than nonprofessional family care; it requires the employment of one or both of the spouses in order to provide an input of 3.5 to 7.9 hours per resident per day. External supports, other than relief services and day programs, would, however, average less than one hour per day per client.

The addition of substantial external supports would make a variant of this model suitable for extremely dependent persons.

Model E: Live-In Staff

This model differs from family care in that the residence is not owned by the staff (who have another principal residence), the staff may only have a professional relationship to each other, and the arrangement involves an hourly salary rather than the purchase of service. Usually one staff member (occasionally two, depending on the number of clients and their needs) would be in the residence 24 hours a day. Staff would not, however, be paid for all the hours (including sleeping hours) spent there but rather for 15 hours a day, according to The Employment Standards Act. For example, a residence in this model could be completely staffed by two persons, each working three days on and four off (averaging 45 hours of paid work per week) plus a relief person. Staff would be expected to carry out assigned duties in the home, but arrangements might be made for them to be away but on call while all the residents were out at day programs.

This model is suitable for two to four clients who are somewhat, quite, very, or extremely dependent, depending on the level of external support provided; it could also occasionally be used for one person with very extensive needs. Staff time varies widely with the residents' needs, perhaps from 3.5 to 10 hours per day per client. External supports also vary but could be extensive.

Model F: Shift-Staffed Residences for Four to Eight Persons

This model is the one usually thought of as a small "group home." It differs from Model E in that it is staffed in definite shifts - either round-the-clock or for all hours excepting those which residents spend at day programs and in that staff members are paid for all hours on duty.

Shift staffing is expensive. Twenty-four hour coverage, 365 days a year, requires a minimum of five staff members who would work a total of 8760 hours per year. Given the desirability of small homes, economy suggests using this model primarily for four to six persons who are quite, very, or extremely dependent and require intensive staff inputs (6.0 or more hours per day). Under special conditions, however, shift-staffed residences may be required for persons who are somewhat dependent.

The reasons for restricting new group homes to a maximum of eight clients have already been detailed, and it is anticipated that larger existing residences will be encouraged to move toward one of the smaller models already described. In general, when it is desirable for one program to provide residential services for more than eight persons, it should be done by using more than one housing unit (apartment, townhouse, or semidetached or detached house) and making staffing arrangements that keep the number of persons in each unit at or below a maximum of four to six.

Occasionally situations may arise in which it is essential to house nine or more persons together. Such circumstances should be clearly documented, and the program or other justification outlined in detail.

RECOMMENDATIONS

1. *All the foregoing models should be eligible for funding by the Ministry of Community and Social Services, the model employed being dependent on the needs of the clients.*
2. *Groups interested in developing new residential programs of all types should be encouraged to submit proposals for programs preferably housing one to six persons in a residential unit but not exceeding eight.*
3. *Only in very exceptional circumstances with clear and strong program justification should more than eight persons share living quarters.*

CHAPTER VI THE FUNDING OF COMMUNITY RESIDENCES

To date, most of Ontario's community residences for the developmentally handicapped have been created for mildly and moderately retarded adults and funded under The Homes for Retarded Persons Act. Under this act, the Ministry of Community and Social Services may pay up to 80 per cent of approved operating costs, and the operator must raise the remaining 20 per cent; this is usually done by charging residents a fee that is deducted from their GAINS-D payments. Children's residences are funded under The Developmental Services Act so that the Ministry pays approximately 94-95 per cent of the approved operating costs. The remaining 6 per cent is derived from two sources: a 3-per-cent charitable contribution that must be raised by the residence operator, and a parental contribution that averages about 2-3 per cent of operating costs.

ISSUES

Two major sets of issues have arisen around the funding of community residences. The first has to do with the need to rationalize and systematize the means by which residential budgets are developed and funds are allocated. The second concerns specific aspects of operating and capital expenditures in such residences.

Funding Issues

1. Program supervisors and consultants sometimes find it difficult to develop budgets for community residences. There are no accepted standards for determining the appropriate relationship between clients' levels of need and the per diems to be paid. Even experience provides few guidelines. This problem is becoming critical as per diems are rising sharply and community programs are beginning to provide services for more severely handicapped persons, who need a considerable amount of care.
2. Current budgeting processes make it difficult to take into account the differing needs of the various individuals within a particular residence as well as the fact that these needs change as residents develop and as residents are admitted and discharged.

Issues Regarding Operating and Capital Expenditures

1. Some concern has been expressed that small, community-based residential programs cannot provide the intensity and quality of care required by more severely handicapped persons in a cost-effective manner.
2. Increases in both rental and purchase costs for residential facilities seem to require some reevaluation of capital-funding policy.

PROPOSED THREE-LEVEL APPROACH TO FUNDING

A new approach to funding, one that separates three major components of residential service for three levels of funding, could go a long way toward resolving some of the funding issues as well as toward rationalizing the entire funding system.

The major objectives would be:

1. Ensuring a stable and dependable funding base for each residential program.
2. Ensuring that the level of funding is very closely related to the level of disability of the persons who reside there and reflects its mandate (as contained in the agreement it signs with the Ministry).
3. Making it possible to separate the costs of room, board, and basic living from program-related costs.
5. Making the available resources flexible enough to respond to the changing needs of residents.
4. Providing program supervisors with a standardized and consistent approach to budget development.
6. Reducing the need for residents to move from their home and friends as their needs change.

The Three Levels of Funding

To accomplish these ends, a system of funding based on three clearly identified, separate areas or levels is proposed: (1) basic living costs (room, board, and other maintenance); (2) basis program costs including staffing; and (3) external support costs (See Chapters V and XII for more detailed discussion of (3)). The principles of this funding system are explained here briefly. Appendix 7 presents an example of how such an approach might work for various models of care and levels of disability; it includes an estimate of basic residential costs.

Level One: Room, Board and Other Basic Living Costs

For adults, basic accommodation costs could be set equal to GAINS-D payments less an amount for comfort allowance. An appropriate rate would have to be determined for children. (Variations might be incorporated in Level-Two funding - Other Program Costs).

Funding on such a basis would provide a standardized rate for basic accommodation and permit clear differentiation between living and program costs. Clear and precise specifications of the costs to be included in the level would be required.

Level Two: Basic Program Costs

Basic program costs would include the costs of both staffing and other program components.

(a) Staffing Costs. Rationalizing staffing costs for community-based residences requires the development of a means of measuring the amount of service required by each client. There are several ways of accomplishing this task (see Appendix 5 for a discussion and Appendix 6 for an example of an instrument using one approach).

Given a standardized estimate of the service required for each resident, it would be simple enough to calculate the requirement for an entire residence, and to translate this figure into the number of person years needed to provide it. The salary scale of the particular organization would then be applied to arrive at the basic staffing allocation.

Since virtually all staff in the new, smaller residences will be direct-care staff, it seems reasonable to include all of them in this staffing computation. If some positions were excluded, the thrust of the approach would be compromised. Flexibility for more highly paid staff and special circumstances (such as the need for ongoing professional input in specialized residences) are built into the suggestions for calculating both Other Program Costs and Level Three funding.

The staffing calculation should be done annually, permitting a budget allocation that remains constant for a year but is then reassessed although all new admissions would be assessed at admission.

(b) Other Program Costs. Other items in Level Two should include budget categories such as communication, advertising, equipment rentals, transportation of staff and residents, staff training, supplementary salaries for more highly paid staff, and perhaps geographical differentials for rent or age differentials for room and board. Also included could be some ongoing professional and other purchased services for which need, amount, and cost can be predicted with certainty. To accommodate differences in program circumstances and objectives, a range would be specified for each residential model, reflecting both current levels of expenditures plus any additional anticipated costs. This range would differ in magnitude from model to model, from as low as zero in parental homes to as much as $10.00 to $15.00 per day in some staffed residences. Current costs in group homes and apartments range from .82 to $17.00, with a median of $6.00.* This does not include supplementary salaries or room and board differentials. This range suggests that some guidelines might be useful.

Level Three: External Support Services and Special Needs

When a client's needs cannot be met by the residence within the Level Two allocations, it should be able to utilize directly (with no exchange of funds) support services including, but not restricted to, those funded by the Ministry (see the discussions of such services in Chapter XII). These should include both professional and paraprofessional services, ranging in intensity from occasional consultation to 24-hour-a-day, one-on-one interventions. The Five Year Plan refers to an increase of such services.

Special Needs Agreements. Gaining access to such support services may require infusion of new funds in some circumstances. Extending the availability of Special Needs Funds to adults in residential programs, at an average of $365 per capita (total additional cost, approximately $1.0 million) would provide the additional flexibility required.

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* These differences may reflect variations in accounting practices as well as variations in actual expenditures.

Separating out the costs of support services and special needs is the component of this funding proposal that provides flexibility to meet the changing needs of individual residents and the new needs of persons recently admitted. When a person's needs change or he or she moves, the services that had been provided would simply be made available to another client within the same geographical area. To some extent, this mechanism would obviate the dilemma created by the desire for clients to move on to less intensive services and the simultaneous wish to preserve personal relationships that may have been built up over long periods of time and/or with some difficulty. Of course, some clients would continue to change residences, but this mechanism would reduce the necessity while making it easier to adjust expenditures in response to changes in need.

THE COSTS OF COMMUNITY RESIDENTIAL CARE

Operating Costs

At the present time, per diem rates in Schedule I Facilities range from $88.00 to $115.00, with a median of $98.00. Capital costs (an estimated $1.50 per day) and services funded by the Ministry of Education (approximately $4.50 per day) raise the actual costs to an average of about $104.00 per day for each of the 5600 beds.* Schedule II daily costs ranged from $67.00 to $128.00 with a median of approximately $77.00; capital and educational expenditures (about $4.00 and $6.00 respectively) brought the total to about $87.00 per day for each of the 1100 beds. Children in both these programs and in community residences also receive an average of $5.50 per day through the Special Needs funds.

The majority of community residential programs serve a less disabled population, and as a result, 1981/2 per diems in community residences for children ranged from $32.00 (some were highly subsidized from other sources) to $140.00 with a median of $57.00, plus an average of $15.00 per day for external day programs (taken over 365 days). New residential programs being brought on in 1982-83 - are averaging $72.00 per day. Existing adult programs averaged approximately $40.00 per day including GAINS-D payments, (new programs are averaging $47.00 per day). Day program cost an additional $12.00 on average. As more disabled clients are served in such residences, costs will, of course, rise.

Table 2 presents examples of costs that could be associated with providing community residential services to persons at each level of disability using a variety of appropriate models. The figures employed are based on actual 1981/2 data for room and board (including comfort allowance) and day-program, and an extrapolation of actual data for other residential costs, as well as stipulated hours of care at stipulated salary rates. The totals should be regarded as reasonably accurate examples although they are certainly not intended to be definitive of actual costs. (Appendix 7 provides a detailed breakdown of the funding for the various models, as well as some explanation and rationale for the amounts.) The table lists the range and midpoint of basic residential and total program costs (special needs plus day-program costs) for each residential model (see Chapter V) at each level of dependency.

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* This figure, however, assumes the average 3.0 hours per day of direct care. The more disabled receive 5.7 hours; given direct-care employees' approximate salary rate of $15,000 per year ($8.00 to $8.50 per hour), daily costs for this group were probably $124 to $126 per day. ($104.00 + 2.7 x $8.00 or $8.50 .)

TABLE 2 EXAMPLES OF POSSIBLE DAILY RESIDENTIAL COSTS (INCLUDING DAY PROGRAMS AND SPECIAL NEEDS)

		Adults				Children				
		Basic residential costs		All program costs[a]		Basic residential costs[b]		All program costs		
Level of disability	Basic residential model	Range	Midpoint	Range	Midpoint	Range	Midpoint	Range	Midpoint	Children in Children's Residences at each level of disability[c]
		$	$	$	$	$	$	$	$	
Somewhat independent (0.0-3.4 hours service)	Own family	13.97 - 15.05	14.51	23.97 - 33.85	28.91	0 - 7.40	3.70	17.50 - 34.90	26.20	29%
	Semi-independent	16.47 - 46.05	31.26	28.47 - 64.85	46.66	- -	-	-		
	Alternative family care	10.00 - 20.00	15.00	22.00 - 45.00	33.50	10.00 - 20.00	15.00	27.00 - 45.00	36.00	
Somewhat dependent (3.5-5.4 hours service)	Own family	13.97 - 15.05	14.51	23.97 - 33.85	28.91	0 - 7.40	3.70	17.50 - 34.90	26.20	18%
	Semiindependent	41.97 - 62.05	52.01	53.97 - 80.85	67.41	-	-	-	-	
	Staffed Residences[d]	36.47 - 67.05	51.76	48.47 - 85.85	67.16	36.47 - 67.05	51.76	53.97 - 94.55	74.26	
Quite dependent (5.5-7.9 hours service)	Own family	13.97 - 15.05	14.51	23.97 - 33.85	28.91	0 - 7.40	3.70	17.50 - 34.90	26.20	18%
	Specialized family care	46.97 - 74.05	60.51	58.97 - 92.85	75.91	44.97 - 74.05	59.51	62.47 -101.55	82.01	
	Live-in staff[d]	40.22 - 63.08	51.65	52.22 - 81.88	67.05	40.22 - 63.08	51.65	57.72 - 90.58	74.15	
	Staffed residences[d]	57.07 - 87.05	72.51	69.97 -105.85	87.91	57.97 - 87.05	72.51	75.47 -114.55	95.01	
Very dependent (8.0-9.9 hours service)	Own family	13.97 - 15.05	14.51	23.97 - 36.85	30.41	0 - 7.40	3.70	17.50 - 37.90	27.70	18%
	Specialized family care	61.97 - 88.05	75.01	83.97 -114.05	99.01	59.97 - 88.05	74.01	85.47 -118.55	102.01	
	Live-in staff[d]	48.97 - 83.08	64.03	70.97 -109.08	90.03	48.97 - 83.08	64.03	74.47 -113.58	94.03	
	Specialized family care and support services	61.97 - 90.05	76.01	83.97 -116.05	100.01	59.97 - 88.05	74.01	85.47 -118.55	102.01	
	Staffed residences[d]	69.97 -103.05	86.51	91.97 -129.05	110.51	69.97 -103.05	86.51	95.47 -133.55	114.51	
Extremely dependent (10.0 hours service)	Specialized family care	73.97 - 88.05	81.01	95.97 -114.05	105.01	71.97 - 88.05	80.01	97.49 -118.55	108.01	7%
	Live-in staff[d]	64.97 - 83.08	74.03	86.97 -109.08	98.03	64.97 - 83.08	74.03	90.47 -113.58	102.03	
	Specialized family care and support services	73.97 - 90.05	82.01	95.97 -116.05	106.01	71.97 - 88.05	80.01	97.47 -118.55	108.01	
	Live-in staff[d] and support services	55.97 - 86.05	71.01	77.97 -112.05	95.01	55.97 - 86.05	71.01	81.47 -116.55	99.01	
	Staffed residences[d]	83.97 -103.05	93.51	105.97 -129.05	117.51	83.97 -103.05	93.51	109.47 -133.55	124.01	

[a] Includes residential plus day-program costs, including those provided by the Ministry of Education for children. Day-program costs are based on actual current annual expenditures taken over 365 days (the per diems taken over 230 operating days are in parentheses) education, $12.00-$20.00 ($19.00 - $31.00); developmental center, $22.00; ($33.00); workshop, $10.00 ($15.50); lifeskills, $17.80 ($27.00). Day-program costs for very dependent and extremely dependent are estimated at $25.00 ($38.50); special-needs costs at $1.00 for adults, $5.50 for children.

[b] Includes Handicapped Children's Allowance for some children living with their own families.

[c] 10 per cent scored less than 50, i.e., were in the category that would be called largely independent in terms of residential-care needs.

[d] Vacations, sick time, etc. would increase staff costs by about 11-13 per cent (about $0.00 - $10.00 per day).

The table clearly shows the cost-effectiveness of the various models. At every level of disability, living with one's own family, is the least expensive model; following are alternative family care, supported independence, specialized family care, live-in staff, and finally shift-staffed residences - in that order. The basic residential costs range from zero for somewhat independent or somewhat dependent children living with their families to as much as $103.00 per day and receiving 10 hours of care per day for extremely dependent children or adults living in a shift-staffed residence. When day program and other costs are included the maximum rises to $133.00.

In the small residences proposed in this paper, virtually all staff would be direct-care staff. Maintenance, dietary, and other such functions would be carried out so that residents could participate in them in whatever ways their current abilities and understanding permit, thus incorporating these activities into programming, and turning them into learning experiences. For example, food, rather than being something that appears mysteriously, would be the result of a series of activities in which residents may have participated, each in his or her own way.

Schedule I Facilities currently average about 3.2 hours of direct care per person per day. One reason for this is that Schedule I Facilities have about 48 percent of their staff involved in direct care, while 34 per cent of their staff are in maintenance, dietary, administrative, and related positions that generally involve very little client contact.* If all these people were involved in direct care, the hours of service would increase to about 5.5 per resident day (an additional 18 per cent of Facility staff are professionals and providers of specialized services).

The last column of the table shows the percentage of children currently in community residences who are at each disability level (as measured by the instrument proposed in Appendix 6). Only 23 per cent were in the very or extremely dependent category. Adults in community residences are less handicapped than children and are capable of doing more things for themselves, so they would require less intensive services at a lower median cost.

Special Needs Funding for Adults

As we have seen, the effectiveness of the proposed three-level system is dependent, to a large extent, on the flexibility provided by the third level and its use of purchased professional and paraprofessional services to meet the needs of particular residents at particular times. This makes effective utilization of such professional and paraprofessional time possible, particularly if residential locations are selected to keep travelling time down (without, of course, putting large numbers together in a very small area). For children in residential programs and in their own homes, external supports beyond those which can be provided by MCSS funded support services and other community agencies, can be purchased through Special Needs funds. No similar mechanism for adult clients exists at present, and although present support services could provide some of what is needed, other funds should be available to purchase some of the required services. Since the adults in residential programs are generally less disabled than the children, they would likely require the purchase of external services less frequently.

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* This figure is based on those facilities that do not purchase a variety of maintenance and dietary services from outside.

In general, access to these funds should probably be subject to similar conditions to those that apply to children's programs, although the procedures manual might need to be modified. Most likely, the residence would apply, on the basis of an individual program plan, for special funds to purchase services.

Legislative Requirements

In some cases, the current provisions of The Homes for Retarded Persons Act would not permit the use of the funding system we have proposed, since it would bring Ministry payments above 80 per cent of a residence's operating costs. Although the proportion of the costs funded under this act could be altered by a regulation change, the greater flexibility of The Developmental Services Act, combined with its less stigmatizing title, might make it more advantageous for funding this and all programs for developmentally handicapped persons. In addition, the Ministry has already approved a recommendation to fund approved homes and supported independence programs under this Act. Thus, all children's residences, Schedule I and II Facilities and adult residences as well as support services could be funded under the Developmental Services Act.

Capital Expenditures

In the last few years, the Ministry has discouraged the purchase of residential properties (either through debt retirement or outright grant) both because of uncertainty about the viability of community residential programs and because it was hoped that many persons in them would move on into independent living. It seems clear that the viability of community programs has been established, but although the clients moving into them may develop significantly, a substantial number is not likely to achieve independent living. Thus, there appears to be an economic argument for the purchase of permanent residences.

Present rental costs add urgency to this need. Particularly in Metropolitan Toronto, they have risen substantially in buildings not under rent control. A recent request would have cost approximately $20 per person per day for rent alone.

Few purchases will be possible, however, unless the ceiling on capital expenditures is raised. The last revision of The Homes for Retarded Persons and the Developmental Services acts set the maximum capital outlay that the Ministry can fund at 80 per cent of expenditures up to a maximum $15,000 per bed. Since then, real estate prices have risen by some 15 to 20 per cent across Ontario and by about one-third in Toronto so that across the province, the average cost per bed in early 1981 was $21,360 for acquisition and $24,900 for construction. This means that capital grants were covering only 70 and 60 percent respectively of the actual costs and probably less than this in Metro Toroto. In addition, as more severely disabled persons are served, the costs of renovations and special equipment, furniture, and fixtures are going to increase substantially.

Given these facts, the recommendations of the Financial Advisory Services paper on the Financing of Agency Capital (July 1982) that where direct capital funding is selected as the most appropriate method of financing a capital purpose proposal, the cost sharing is to be based on percentage of approved costs rather than on fixed dollar per unit or on ceiling units presently prescribed in the legislation seems to make a great deal of sense, if appropriate safeguards can be developed.

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If the capital-expenditure regulations are to be changed to meet present conditions, they could also be adapted to provide financial incentives for establishing small programs. For example, capital funds could be provided on a basis as similar to the following:

(a) 90 per cent of approved capital costs for residential programs for four persons or fewer.

(b) 80 per cent of approved capital costs for residential programs for five to eight persons.

(c) 70 per cent of approved capital costs for residential programs for nine or more persons within one living unit.

Funds for furniture, minor renovations, special equipment, and fixtures relating to accessibility and increased independence in rental equipment could be made available on a similar basis.

RECOMMENDATIONS

1. *The three-level system of funding described in this chapter should be examined for its applicability for all community residential services for developmentally handicapped persons. To this end:*
    - *(a) Clear and precise specifications of the costs to be included in Level One would need be developed.*
    - *(b) An instrument such as the one described in Appendix 6 would also need to be developed and undergo further testing for its usefulness in determining the level of disability of all developmentally handicapped persons in residential care.*
    - *(c) The precise relationship between the level of disability of residents and residential staffing requirements would need to be determined.*
    - *(d) The components of Level Two's other program costs would need to be specified, and criteria, guidelines, and ranges developed for each.*
2. *In order to increase cost-sharing, adult community residences should place increased reliance on providing services through external staff employed by support services or by purchase of services from other professionals and agencies.*
3. *Funds should be made available in MCSS Area Offices to meet the special needs of adults living at home or in community residential programs on a basis similar to that used for children.*
4. *A review should be made of the advantages and disadvantages of funding all residential programs for the developmentally handicapped under The Developmental Services Act*
5. *The recommendation of the report on the Financing of Agency Capital that, where direct capital funding is selected as the most appropriate method of financing a capital purpose the Ministry's cost would be based on percentage of approved costs rather than on a percentage of a legislatively stipulated ceiling, should be accepted if appropriate safeguards can be developed. To reinforce policy directions, this recommendation could, for example, be applied as follows:*
    - *(a) 90 per cent of approved capital costs for residential programs for four persons or fewer.*
    - *(b) 80 per cent of approved capital costs for residential prorams for five to eight persons*
    - *(c) 70 per cent of approved capital costs for residential programs for nine or more persons within one living unit.*

CHAPTER VII RESIDENTIAL SERVICES FOR THE MILDLY AND MODERATELY RETARDED PERSONS

The community residential services which have been developed to date primarily serve persons who are mildly and moderately handicapped, and the majority of the persons currently in Facilities for whom new community places will be required by the Five Year Plan will also fall in these categories. About 11 per cent of the 3200 residential beds in place as of September 1981 are for children while the remaining 89 per cent are occupied by adults. These programs are funded through the Developmental Services Act and The Homes for Retarded Persons Act respectively.

ISSUE

Many persons whose developmental handicap is mild or moderate also have additional difficulties (behavioral/emotional problems, sensory impairments, problems associated with age, and so on). Issues regarding residential services for them are detailed in other chapters of this paper. Here we focus on one issue only:

> What steps can be taken to ensure that mildly and moderately handicapped persons are provided the type and intensity of residential services they require?

BACKGROUND

The Client Group

Of the Ontario residents identified as developmentally handicapped, approximately 80 per cent - about 56,000 individuals - are mildly or moderately so. Unless they have serious behavioral, physical, or medical problems, they could probably be described as independent, somewhat independent, or somewhat dependent. Although their academic achievements may be limited and substantial individual differences exist, most such persons are capable of acquiring a variety of self-help, social, community-usage, and vocational skills through a combination of experience and effective training programs.

Service Development to Date

Most existing group homes and apartment programs, developed in response to the late 1970s' thrust for deinstitutionalization, serve the mildly and moderately handicapped. These clients also find accommodation in a variety of other community residential services, including children's boarding homes, private boarding homes, hostels, foster care, and homes for special care. (The exact number served by these alternatives is not known. Many are privately operated for profit, and others have no direct government funding.) Others continue to live with their parents.

Nevertheless, approximately 2400 mildly and moderately retarded individuals still reside in Schedule I and II Facilities. About 1700 of them do not have any serious behavioral, physical, or medical handicaps.

TYPES OF RESIDENTIAL SERVICE

With the exception of individuals who have additional handicaps, the mildly and moderately handicapped have residential needs not unlike those of the general population. Indeed, most mildly retarded adults can and do live independently without specialized services. Moreover, the expansion of workshops, life-skills training and other support services during the last decade could, with the expansion of special educational services proposed for this decade, make it possible for an increasing proportion of this group to live independently.

Unfortunately, individuals who have demonstrated the capacity and the desire to live independently have frequently been deterred from doing so by a financial disincentive created by the GAINS-D program. A client who moves out of a group home or an apartment program has his or her income significantly reduced. This problem should, however, be resolved with the implementation of the MCSS policy paper on creating income equity between apartment program residents and persons living independently.

Medical problems sometimes create another barrier to independent living. Some clients may well reach a satisfactory level of competence in all areas but continue in residential care because of a medical problem that occurs infrequently. The use of a service such as Protect-Alert could well enable such individuals to move to independent living.

Even if such problems can be resolved, there will continue to be a need for residential programs for a significant number of persons with this level of handicap, particularly those who are moderately handicapped, only a few of whom are likely to live independently. The wide range of these clients' needs can probably best be met by using Models A to E described in Chapter V, particularily their own family (A) and alternative family care (C) for children, and supported independence (B) for adults.

Persons with this level of handicap should live in shift-staffed group homes (Model F) only if: (1) it is impossible to recruit family-care providers, live-in staff, or external supports; or (2) they suffer from behavioral/emotional, sensory, or physical problems that external support services (as described in Chapters V, IX and XII cannot respond to adequately.

Most mildly or moderately handicapped children who have no additional problems can be maintained in their own homes if appropriate support services can be provided. Even alternative family care may be used relatively infrequently here.

Program Content

Residential programs for this client group should be primarily directed toward increasing client competence to an age-appropriate level in the following life skills: (1) communication; (2) socialization and interpersonal skills; (3) basic hygiene, self-care, and care of clothing; (4) housekeeping, room management, and domestic skills; (5) food selection and preparation; (6) use of leisure time and community recreational facilities; (7) use of money and budgeting; (8) use of public transportation, when available; (9) use of medication; (10) recognition of hazards in the home and outside; (11) community-usage skills, such as shopping and restaurant behavior; and (12) coping with emergencies. For the individual client, the program should reinforce and build on existing skills while reducing dependence in those areas in which he or she lacks competence. The program should also provide ample opportunities for contact with families and friends outside the residence as well as for integration with the general nonhandicapped population.

Some adults in this client group may attend life-skills programs during the day, but given effective use of the training technologies now available, most are capable of achieving substantial vocational competence and finding remunerative employment, many in the competitive labor market, others in a sheltered setting.

Staffing

Staffing levels for somewhat independent and somewhat dependent persons are described in Chapter VI and in Appendix 7. Preferably, all primary caregivers should have successfully completed a Mental Retardation Counsellor course, and they certainly should have knowledge in the following areas: (1) development and implementation of individual program plan; (2) growth and development patterns; (3) application of principles of learning; (4) recognition of client needs and wishes; (5) nonverbal communication; (6) basic first aid; and (7) behavior-management principles. Program staff should also have the ability to work with minimal supervision and effectively use consultants and other community resources.

RECOMMENDATIONS

1. *In the absence of serious complicating factors, persons with this degree of handicap who cannot live independently or with their families should be admitted to the less intensive types of residential care, such as alternative or specialized family care or live-in staff for both children and adults, as well as semi-independent living for the latter.*
2. *For persons who have this degree of handicap and no serious complicating conditions but are already in a more intensive form of residential care, efforts should be made to relocate them to the less intensive forms appropriate to their needs (as described in Recommendation 1) or to change the intensity of the programming provided them.*
3. *Training programs in assessment, goal formulation, individual program planning, and behavior-change techniques envisaged under the Individual Program Planning initiative should be implemented so that residential staff in programs for mildly and moderately handicapped persons can help them acquire a substantial range of the life skills described in this chapter.*

CHAPTER VIII RESIDENTIAL SERVICES FOR ELDERLY MENTALLY RETARDED PERSONS

Canadian society is undergoing a major shift in its demographic structure: an increasing proportion of the population is over age 65 because of both lower birth rates and increased life expectancy. The trend toward a higher average age is apparent among those segments of the population that are developmentally handicapped. As a result of advances in health care and the general improvement in standard of living, these people are no longer likely to die in the second or third decade of life, as was the former norm. Their life expectancy depends partly on the degree of disability and partly on their living conditions and the quality of care they receive. Although severely or multihandicapped people may still have a significantly reduced life expectancy, mildly handicapped people in good living conditions can generally live out a normal life span.

As these people age, however, they tend to face a kind of double jeopardy. They must cope with all the problems associated with old age and, in addition, with the rejection and discrimination that most individuals with mental disabilities suffer.

ISSUES

Over the coming decades, it will be a considerable challenge to ensure the right of aging mentally retarded persons to the same satisfactory quality of life and living arrangements as the rest of the aging population. Issues that must be faced soon include:

1. The number of elderly retarded people is increasing, creating a new demand for residential services.
2. Like other elderly people in the population at large, these individuals have special needs for social services. In particular, their lives are subject to disruption by events, such as the loss of a caregiver or deterioration of health, that require anticipatory planning, especially in relation to the provision of residential services.

BACKGROUND

The Client Group

Although we lack clear statistical evidence of increased life expectancy for the developmentally handicapped, there are many indications of this phenomenon. The proportion of elderly people in Ontario's overall population is increasing rapidly. In 1980, 10 per cent of the total - 840,000 persons - were 65 or older; projections show that it will be 14 per cent in 2001 and 20 per cent - more than two million persons -in 2021. We can expect a significant number of them to be developmentally handicapped.

Even now, the group is sizable. An index population calculated for 1980 (referring to the number of individuals most likely to require social-service supports), indicates that Ontario has 9955 mentally retarded persons over age 45,* 6117 over age 55, and 3131 over age 65. Thus, a population of almost 10,000 may need at least some special services; only about 1000 of them are in Schedule I Facilities.

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* The mentally handicapped, especially the severely handicapped, must receive attention related to aging by the time they reach 45. Planning for their needs beginning at this age takes into account our limited knowledge of their expected life span as well as the life expectancy of their parents who may be the primary care givers.

Moreover, Canadian data show that more and more individuals who are retarded and over age 50 are coming to the attention of governments, agencies, and associations for the mentally retarded (often for the first time, even though some have lived in the community all their lives) and that older residents of institutions are returning to their homes and local communities. Combined, these two phenomena make quite clear the need for appropriate organizations to be aware of this "new" area of service demand.

The Problems of Aging for the Developmentally Handicapped

Like other aging people, the aging retarded may experience diminution of energy, deterioration of health, loss of strength and dexterity, exclusion from previous activities, death or loss of friends, caregivers, and relatives, sudden relocation, enforced or unfulfilling leisure time, or changes in familiar and cherished life patterns. They may be troubled by fears of death, abandonment, loss, loneliness, lack of necessary supports and services, rejection, or simply neglect. In general, these "events" are characterized by either loss or anxiety. They need to be anticipated and aids planned on an individual basis.

Accommodation is, therefore, a key issue. Its resolution depends not on chronological age but on the individual's degree of handicap, general health, and specific disabilities, as well as the availability of support inside and outside the family. The effects of aging vary with these factors and also with the social environment and quality of care.

Residential services for older retarded people need to take into account the basic needs they share with other aging people:

1. Maintenance of the personal identity developed throughout life.
2. Scope for independent action and free choice to the full capacity of their abilities and situations.
3. Social interaction within and beyond the family - having friends, being involved in the life of the neighborhood and wider community, establishing and maintaining new relationships.
4. Access to privacy and personal possessions, and choice in the organization of personal environment.
5. A concern with their quality of life on the part of those who serve them.*

These needs can best be met if the appropriate living skills have been learned and reinforced throughout life.

Service Development to Date

In General

In most developed countries, the majority of older people maintain their own residences. Approximately 85 per cent of persons over 65 live independent of government-based residential services. Even for those who are ill, the amount of care provided by families is much larger than that provided by the public or voluntary sectors. In the United States, for example, the 5 per cent of persons age 65 and over who are in institutions at any one time are outnumbered two to one by equally disabled older persons who live in the community, most of them in the homes of their families.

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* Adapted from the Position Paper of the Task Group on Aging and Mental Handicap, International League of Societies for Persons with Mental Handicap (1982).

This general pattern of social support and care holds true for older persons with mental disabilities.* This fact has significance for service provision to the retarded who are elderly (age 45 and older) for a number of reasons.

First, the majority are likely living at home with family members as their primary caregivers.

Second, the impact of the caregiving role is substantial. Studies point to the need for support to families that provide care to dependent older persons, including those who are mentally retarded. Some countries have developed innovative approaches to providing respite care and home-help services, as well as housing policies that encourage multigenerational living and various forms of financial assistance for family caregivers. Japan, for example, gives low-interest loans to families who add or remodel an extra room to house an elderly relative. In Sweden, a family can receive an allowance of up to $5000 to adapt its home and buy special equipment to meet the needs of a disabled elderly relative.

Third, of the elderly who are institutionalized, a significant percentage are single people who have no spouse or close living relatives. These people are among those most in need of support and residential services if they are to return to their home communities.

In Ontario

Provincial policy for the elderly has three major thrusts: (1) to encourage and help them to remain independent in the community; (2) to protect them from expenses associated with aging, such as high health costs; and (3) to provide care for the minority who are unable to live in the community.

Instruments include general health services, income support, and the following programs related to residential needs:

Home Care: A coordinated program of home health services (for example, nursing and physiotherapy) and allied services, such as homemaking.
Home Support: Programs that cover support to daily living and related social activities (meals-on-wheels, elderly person centers, home maintenance.
Residential Care (Homes for the Aged): Provision of supervised accommodation in homes for the aged.
Extended Care (Homes for the Aged, Nursing Homes): Provision of nursing and personal care in the residential setting of a nursing home or home for the aged.
Chronic Care (Hospitals): A rehabilitation-oriented continuing-care program in health facilities (including chronic units of hospitals and chronic hospitals).
Assisted Rental Housing: Rent-geared-to-income housing, provided by public, nonprofit, and private corporations.

Data on how many developmentally handicapped persons use these services are difficult to obtain.** In 1975, approximately 1000 such people lived in Homes for the Aged or Nursing Homes, and about 1200 persons over 55 in Homes for Special Care.

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* These data taken from Mary Jo Gibson, "Family Support Patterns, Policies and Programs in Developed Nations," presented at the annual scientific meeting of the Gerontological Society of America and the Canadian Association on Gerontology (Toronto, 1981).

** Data are not currently collected on how many of the individuals in Homes for the Aged or Extended Care Beds are mentally retarded. OAS/GIS records are no help since the criteria for these benefits are age and financial need, in contrast to Family Benefits, whose criteria include disability and dependent children. Thus when the retarded are transferred from social assistance to income support for the elderly, data on the client population are no longer available.

To date, the Metropolitan Toronto area has two specialized group homes for older retarded persons; other group homes for the retarded throughout the province include some older individuals.

TYPES OF RESIDENTIAL PROGRAMS

As we have seen, various levels of government provide a range of home support services and residential care for the elderly. For clients who are also retarded, the merits of these regular services must be judged on a case-by-case basis. When it is in the best interests of the individual to remain in a family or group home, he or she should be helped to remain there with additional supports and resources. When it is necessary to relocate the person, integration into a regular residential facility should be considered whenever care for the handicapped person can be satisfactorily integrated with its care for other elderly persons. As Appendix 8 shows, the needs of the elderly who are retarded are, in many respects, not very different from the needs of those who are not.

The regular services for the elderly cannot, however, meet the elderly retarded's spectrum of accommodation needs; neither can the existing services for the retarded, most of which are oriented to younger age groups. Professionals and agencies in the latter field must give more attention to the special needs of the elderly handicapped by means of active outreach to individuals in the community. Adult Protective Service Workers should be key resources in such out-reach.

The elderly retarded can and do fit into all the residential models discussed in Chapter V, but additional support services may be required. Depending on the individual, the issues that need to be addressed may include estate planning, retirement, living arrangements, use of leisure time, family members' changing responsibilities, future advocacy, and emotional support needs. Each plan should focus upon anticipation and prevention of unnecessary disruptive events.

In addition, the need is identified for two kinds of specialized group homes that would provide supervised accommodation and programming specifically for elderly retarded persons. It is recommended that 20-25 of the group home spaces per year that are scheduled for development in the Ministry's Five Year Plan be designed or converted to the specialized or transitional homes for elderly retarded persons described below.

Specialized Community Residence for the Elderly Retarded

A specialized residential program should provide long-term homes for older retarded people who wish to live with others of their own age. They would follow the general Models E or F but differ from many adult group homes in having 24-hour staffing to permit flexibility in the day program; presumably, some residents would stay at home part time or full time if they were retired or unable to participate in a day program.

The size of such homes should follow the principles recommended in Chapter I of this paper; the maximum number for group-home living is eight, and every effort should be made to maintain small, family-like settings.

This specialized program for group living could use a number of physical arrangements, including apartment clusters. The emphasis should be on innovative approaches to creating integrated living situations that meet individual needs of elderly people.

Program Content

The specialized residence should meet the primary need for a stable home that offers stimulation and activity in a supportive environment where the individual can maintain the skills he or she has. Opportunity for social interaction should be high, and outreach to other older retarded people in the community a priority. The principles of the program should be access to privacy and personal possessions and organization of the personal environment.

The program should include physical and recreational activities, counseling particularly related to education for the aging, and skill development in areas typical of most group homes, such as budgeting, self-care, use of community resources, and so on. Also, incorporated into the program should be preventive and rehabilitative health care, including activities designed to prevent or delay the development of apathy and immobility, which frequently lead to deteriorating health, dependence, and the need for nursing care among older people.

Staffing

The most important prerequisites for the staff of such a residential program would be interest in the aging and in mental retardation and a positive, dynamic attitude toward the potential of elderly people. Knowledge in the field of gerontology could be acquired through experience and/or academic courses in gerontology; it should be combined with the knowledge of mental retardation normally acquired through completion of a recognized course of study.

Transitional Home for Elderly Retarded Individuals Discharged from Institutions

Experience has demonstrated that some retarded individuals, particularly those who are mildly or moderately handicapped, who have been residents of institutions for many years adjust to and prefer community living in small, more normal settings when given the opportunity. Candidates for such moves are likely, however, to need considerable help in making the change. A transitional home would provide a short-term (two- to five-year) training program for retarded individuals age 45 and older who have been discharged from Facilities or other institutions. The number of residents should be small, in order to provide maximum attention to individual needs.

Program Content

The purpose of the transitional program would be to provide specialized training in the activities of daily living, social and emotional development, and independence. The program should give particular emphasis to social skills, behavior training, and stimulation through social and recreational activities.

After a relatively short period, this intensive training geared to older persons' special needs should enable placement of clients in one of a variety of settings - a regular group home, an apartment program, even an independent living arrangement.

Staffing

Staffing considerations for such transitional homes would be essentially the same as those outlined for the specialized group-home model.

Such homes would require back-up resources from behavior-management programs and/or professional consultants.

RECOMMENDATIONS

1. *The following general principles should be adopted by the Ministry of Community and Social Services in the development of services to elderly retarded people:*
    (a) *As retarded people join the ranks of senior citizens, the services and programs provided for them should proclaim their enhanced status rather than the all-too-frequent diminishment of worth that present practices suggest.*
    (b) *Aging retarded people and their families should be identified and offered help in order to anticipate and plan for the problems of the future.*
    (c) *Maximum continuity of familiar life patterns and social supports should be encouraged.*
    (d) *When major life changes are inevitable, program and service options providing the greatest lifestyle continuity, stability, and the least possible loss of familiar "anchors" are to be preferred to those only emphasizing developmental growth, although a combination of both is best whenever possible.*
    (e) *Every effort should be made to avoid placing an aging retarded person in an institution.*
2. *The Ministry should encourage the development of small group homes and supported living arrangements for elderly retarded people, including transitional homes for those discharged from Facilities.*
3. *A planned, specific, active outreach should be made to aging retarded people in all living arrangements -independently, with parents or family members, in community homes, and in Facilities. Information and assistance in planning for the future of each individual should be made available. The main thrust of this outreach should be effected through the Adult Protective Service network.*
4. *If present living arrangements no longer meet the needs of an aging retarded person, the plan for his or her future should emphasize the following options:*
    (a) *Provision for the present home to adapt on a planned basis, through the addition of special supports and resources as necessary.*
    (b) *Relocation, at the option of the individual, into a regular high-quality home for the aged or nursing home. This option is particularly important for high-functioning persons and/or those who wish to move together with a close friend or family member.*
    (c) *Relocation into group living arrangements consistent with particular needs. The client should be involved in planning and should move with friends whenever possible.*
5. *The needs of aging retarded people should be drawn to the attention of planning and service delivery bodies throughout Ontario.*

CHAPTER IX SERVICES FOR EMOTIONALLY/BEHAVIORALLY DISTURBED PERSONS

The developmentally handicapped are as prone to behavioral and emotional disorders as individuals of "normal" intelligence. Indeed, some researchers suggest that the former may have an even greater likelihood of becoming behaviorally/emotionally disturbed because of the many frustrations they experience.

When developmentally handicapped persons manifest problem behavior, many caregivers - staff of community residential programs, as well as parents - feel themselves inadequately prepared to deal with it; moreover, they are often concerned about its disruptive effects on other residents and possible negative reaction from the community at large. Thus, persons with such problems fall into the "Hard to Serve" group referred to in the Five Year Plan.

Services for disturbed retarded adults are very limited in Ontario. For children, the number of behavior-management programs has increased in recent years to approximately 30, but in many areas, consultation is not available rapidly enough or in sufficient intensity to help parents, foster parents, and group-home staff to deal effectively with problems or to feel confident in making the attempt. Often they feel their only option is seeking to have the "problem" person admitted to a Schedule I or II Facility.

Large, specialized institutions will continue to be required, but doing more to provide alternatives would reduce both disruptions to clients who manifest problem behavior and the number of admissions to specialized facilities.

ISSUES

The provision of community-based services for persons who are behaviorally/emotionally disturbed and developmentally handicapped encounters two kinds of problems in Ontario:

1. Few residential programs are able and willing to serve individuals who are behaviorally/emotionally disturbed. Among the reasons for this is the scarcity of psychiatric, psychological, and other support services that could assist residential staff in coping with problem behaviour. Crisis and emergency admissions to general-hospital and other psychiatric programs are difficult to obtain; so is adequate follow-up. Finally, many residential staff lack training in dealing with behavioral/emotional disturbances.
2. The Division of responsibility between the mental health and mental retardation systems for serving the developmentally handicapped who are behaviorally/emotionally disturbed is currently somewhat unclear.

BACKGROUND

The Client Group

Although precise data on the number of behaviorally/emotionally disturbed in Ontario are not available, a recent survey identified 800-1000 residents of Schedule I and II Facilities as disturbed (see Appendix 9 for a description of the types of behavior included); 300 of them were regarded as dangerous to themselves or others. In addition, some 1100 persons, primarily children, are receiving behavior-management services in the community. The Metro Toronto Association for the Mentally

Retarded (MTAMR) finds that 30 per cent or more of the adults in its programs have some form of emotional disturbance. The Waterloo District Working Group identifies a comparable figure, and it is consistent with data from studies in other jurisdictions. Clearly, a substantial proportion of developmentally handicapped persons have behavioral/emotional problems.

Service Development to Date

In General

The increasing evidence that certain aspects of large institutions - crowding, lack of private space, and lack of stimulation - increase the frequency of behavioral/emotional problems has resulted in attempts to provide disturbed clients with residential services outside institutional settings. For the developmentally handicapped, initial efforts to reduce problem behavior used both psychotropic medication and social learning techniques; more recent behavior-management techniques are more sophisticated and rely less on the use of aversive procedures.

As a result of these developments, a number of U.S. jurisdictions (Nebraska, Pennsylvania, Massachusetts, and others) have expanded their services in the area of community residential settings for developmentally handicapped persons with behavioral/emotional problems.

In Ontario

Only three residential programs in Ontario provide services specifically for the developmentally handicapped who are also disturbed. MTAMR operates a four-bed residence in Toronto; York Central AMR, a five-bed residence for children; TYRO, an adolescents' residence at Thistletown.

On another level, the Ministry of Health has four evaluation units (170 beds) that provide three- to six-month programs for "mentally ill" developmentally handicapped adults. These units primarily serve the needs of the Facilities, and the community has little access to them. Moreover, they take only patients who have been diagnosed as "mentally ill" in the conventional psychiatric sense. Many forms of severe behavioral disturbance do not qualify a client for admission.

In case of behavioral/emotional crisis, neither general hospitals nor mental health facilities readily admit developmentally handicapped people. As a result, community-based residential services are reluctant to take disturbed persons into their programs as they realize little back-up is available. And when problems develop, many attempt to have the individuals admitted to Schedule I or II Facilities.

TYPES OF RESIDENTIAL SERVICES

Many behavioral/emotional problems among the developmentally handicapped can be dealt with more effectively and efficiently in residential settings than in institutions. In the majority of cases, any of the general models described in Chapter V could cope with these problems if support systems were available. In a few cases the answer will be specialized residences geared to clients with problem behaviors.

External Supports for Behaviourally/Emotionally Disturbed Persons in Non-Specialized Residential Programs

If residences are to be encouraged to deal with a greater proportion of persons with behavioral/emotional problems than they do now, then their staffs must have access to experts who are knowledgeable about such problems, they must have the skills to work with these consultants and to carry out the programs they design, and they must have the back-up of knowing that alternative settings are available in emergencies.

Consultant Assistance to Non-Specialized Residential Programs

Residences on any of the general models should be eligible to consult experts regarding residents who enter with or develop behavioral/emotional problems. Usually these consultants would be psychiatrists, registered psychologists, or master's-level persons with expertise in behavior-management, although some may be from other disciplines.

A behavior-management consultant's primary duties would be to undertake environmental-behavioral analyses, design programs (in consultation with program staff), monitor their implementation, and review their effectiveness. If an individual's program requires intensive services, the residence staff should be able to obtain extra staff assistance on a short-term basis.

In order to ensure both program consistency and consultant accountability, residential programs should enter into specific contracts with consultants regarding goals, procedures, respective roles, and so on for each client for whom a detailed behavior-management program is developed.

Environmental Analysis in Non-Specialized Residential Programs

When behavior-management consultants embark on planning programs, they should examine an often-ignored area: the environment as a cause of or a contributing factor to problem behavior. The majority of the programs designed to deal with such behavior have proceded, with varying degrees of success, on the assumption that since it emanates from the individual, the design should focus on doing something to that person to change his or her behavior. However, actions in a particular environment reflect the behavior-shaping nature of the environment itself, as well as the characteristics of the individual. For example, a growing body of evidence indicates that the amount of space available per person correlates negatively with the frequency of aggressive behavior. Similarly, the amount of stimulation available in an environment, in terms of both physical surroundings and the nature and variety of available activities and interactions, has been shown to affect the frequency of undesirable behaviors, including aggression and hyperactivity. Moreover, an increasing number of researchers claim that more highly "normalized" environments (as measured by PASS or some variant thereof) create more highly developed coping skills. To the extent that adaptive and problem behaviors are incompatible, an environment in which such adaptive behavior is developed is one in which maladaptive behaviors are less likely to occur.

Physiological factors must also be included in evaluating the environment of a developmentally handicapped person. Physical disorders, including infections and gastrointestinal upsets, have been found to lead to problem behavior, especially among the more severely disabled who cannot articulate sources of discomfort.

All these findings suggest the wisdom of using consultants to identify aspects of the internal-physiological, social, and physical environment that may be influencing behavior. Such analysis may provide information relevant to the development of programs for "problem" individuals and to the prevention of maladaptive behavior in others. Moreover, it may suggest relatively simple and inexpensive solutions; for example, it is not difficult to provide medical and dental check-ups for the inarticulate (see Appendix 10 for an overview of some of the kinds of environmental analyses that might be undertaken).

Program Content in Non-Specialized Residential Programs

A primary task of the consultant experts in behavior change should be the design of individual programs, as necessary, for any residents with behavioral/emotional problems. Several approaches seem desirable:

1. Any program aimed at eliminating problem behavior should also emphasize the development of alternative behavior that is more desirable and incompatible with the problem behavior.
2. Psychotropic medications and other psychophysiological treatments are among the most demonstrably effective means of reducing depression, anxiety, and the frequency and severity of a number of psychotic behaviors. A psychiatric consultant, preferably one who is familiar with the developmentally handicapped, should take responsibility for prescribing and monitoring dosages.
3. If staff can help clients to increased adaptive functioning, the frequency of problem behaviors is likely to decrease. Therefore staff should be familiar with the basic principles of counseling and behavior change and become competent in using these techniques under the direction of a consultant or supervisor.
4. Other than DRO (Differential Reinforcement of Other Behavior), techniques designed to reduce the frequency of problem behavior should be implemented only in accordance with a set of standards for their use in community settings. The use of such procedures should require the approval of a registered psychologist, a master's-level coordinator, or the director of a behavior-management program. This would permit the use of contingent-education techniques (contingent observation, educational fines, and overcorrection), nonexclusion and exclusion timeout, restitution, and fines. Response-contingent electric shock and confinement should probably not be used in community programs.
5. If a client attends a day program outside the residence, the staff of that program must be involved in any plans for changing behavior. If the problem behavior does not occur in the external setting, its staff should at least be informed, through their participation in the individual program plan development, so if it does begin to occur there, they will be aware of the importance of informing the residence's staff. If the behavior occurs in both environments, the day staff should be more actively involved in the planning and implementation of the program and should have appropriate access to the services of the consultant and any involved additional resource staff.
6. In many instances, the most appropriate form of intervention will reflect an interaction between the level of intellectual functioning and the nature of the behavioral/emotional disorder. Since many of these interactions are not well understood, programs and persons providing such services should be encouraged, perhaps through research grants, to document in detail the techniques employed and their success with persons at various levels of intellectual handicap.

Emergency and Crisis Services

If a developmentally handicapped person who engages in disturbed behavior is to be maintained in a regular residence, the staff must have the confidence that comes from knowing an alternative setting (a secure one, if necessary) is readily available to them for short-term admission in case of a crisis involving life-threatening or extremely disruptive behavior. Such a back-up could be a general hospital psychiatric unit, a special residential program, a Schedule I or II Facility, or a psychiatric hospital. Whenever possible, a residence should have such an arrangement with more than one such facility.

Family Counseling and Home Behavior-Management Programs

When a client is living with his or her parents (or when it is desirable that he or she return to them), it may be essential to provide them with some counseling and behavior-management assistance.

Staffing

In nonspecialized residences that develop programs to deal with behavior problems, all staff members should have an understanding of the principles and techniques of behavior change and counseling sufficient to enable them to assist the consultants in planning individual programs and to take responsibility for their implementation. Staff-to-resident ratios can be similar to those in other nonspecialized residences for persons with similar needs.

Specialized Residences for the Behaviorally/Emotionally Disturbed

Admission

Many prescriptions for dealing with behavioral/emotional problems focus largely on the development of special residential programs and units for persons who manifest such problems. However, with the developmentally handicapped as with other people, problem behaviors differ substantially in their type, frequency, and severity. Many do not really have an enormous impact on other people or represent a great danger to the disturbed individual. Placing the individual in a specialized setting has advantages, but most of them accrue to other persons, and many of them are substantial only for certain types of severe problems. (Appendix 11 gives a list of the advantages and disadvantages of using specialized programs.) More often than not, the developmentally handicapped person who is behaviorally/emotionally disturbed is better off in a regular residence that has a program for coping with such problems.

Clearly, however, there are instances in which admission to a specialized program is necessary to protect clients, to prevent disruption of programming, and to provide effective programming. These circumstances occur:

1. When the person is a danger to himself or herself and requires a secure environment for self-protection.
2. When the person is a danger to others (residents, staff, other persons in the community) and is required to be in a secure environment for their protection.
3. When the person's continued presence in his or her regular environment will very substantially disrupt the programming or reduce the quality of life for other residents.

4. When the problem is a severe one that has shown itself intractable in the person's regular environment, and the only program alternative(s) cannot be provided on an out-patient basis.

Admissions to specialized programs should, of course, be regarded as temporary placements. The focus should be on the client's reentering a more normal environment as soon as possible.

Programming

Each of the general models D, E, and F described in Chapter V could be appropriate for a specialized residential program for some developmentally handicapped persons with behavioral/emotional disorders. The locations may be urban or rural. If the program is to accommodate persons with fairly disruptive forms of behavior (screaming, aggressiveness, and so on), a detached house may be the most appropriate setting; if only less disruptive problems are to be dealt with, a semidetached house, townhouse or apartment can be considered.

Larger residential programs (five to eight beds) should usually attempt to provide one bed that other residential programs in the area can use in an emergency.

Programming must, of course, be individualized, and extensive psychological, psychiatric, and other professional consultation services are required; some programs may need to have a psychologist on staff.

Staffing

The staff for specialized community residences must have extensive training in the analysis of and programming for problem behaviors. They must be proficient in behavior management techniques, as well as in crisis intervention, emergency medical skills, and physical protection and restraint methods. They must also participate in planning the reintegration of their clients into regular residential settings to ensure that the gains they have helped them achieve generalize to that setting.

Direct-care staffing ratios should be similar to those recommended for special units in Facilities and would reflect the level of disability of the resident.

RELATIONSHIPS WITH THE MINISTRY OF HEALTH

There has been a lack of clarity regarding whether the Ministry of Health or the Ministry of Community and Social Services should be responsible for persons who are both emotionally disturbed and developmentally handicapped. At the moment, they often fall between the two. Although the Ministry of Health does not actively exclude them, most people who are moderately to severely developmentally handicapped do not meet the criteria for many of its programs. For the most part, the mental health service system assumes that their psychiatric needs are being met (or should be met) by the mental retardation service system. Yet, those who work in the latter system often do not feel competent to manage some of the behavioral/emotional disturbances of their clients. Table 3, which follows, is a very preliminary attempt to develop some guidelines reflecting current professional opinion on the circumstances under which the various levels of residential care and treatment are most appropriate (See recommedation 12 below).

TABLE 3 TYPE OF BEHAVIORAL / EMOTIONAL PROBLEM RELATED TO SPECIALIZED RESIDENDIAL AND TREATMENT SERVICES

	Category of service				
	1	2	3	4	5
	General residential or day service with external consultation*	Temporary (less than 90=day) admission to specialized community residence or general-hospital psychiatric facility	Temporary (less than 180=day) admission to psychiatric hospital or special Facility unit	Longer-term admission to specialized community residence or general-hospital psychiatric facility	Longer-term admission to psychiatric hospital or special Facility unit
Aggression (persons)	Low to medium frequency; low to medium severity	Medium to high frequency; medium severity	High to very high frequency or severity, or if nothing in Category 2 available, or if behavior so dangerous that secure environment is required	If Category 2 has been inadequate	If Categories 2, 3, or 4 are inadequate, or if behavior is so dangerous that secure environment is required
Aggression (physical environment)	Low to medium frequency; low to medium severity	Medium to high frequency and severity	Very high frequency or severity, or if nothing in Category 2 available, or if behavior so dangerous that secure environment required	If Category 2 has been inadequate	If Categories 2, 3, or 4 are inadequate or if behavior is so dangerous that secure environment is required
Aggression (self-injurious)	Low to medium frequency	Medium to high frequency; medium severity	High or very high frequency or severity, or if nothing in Category 2 available, of if behavior so dangerous that secure environment required	If Category 2 has been inadequate	If Categories 2, 3, or 4 are inadequate or if behavior is so dangerous that secure environment is required

	Category of service				
	1	2	3	4	5
	General residential or day service with external consultation*	Temporary (less than 90=day) admission to specialized community residence or general-hospital psychiatric facility	Temporary (less than 180=day) admission to psychiatric hospital or special Facility unit	Longer-term admission to specialized community residence or general-hospital psychiatric facility	Longer-term admission to psychiatric hospital or special Facility unit
Aggression (verbal)	Low to high frequency; low to high severity	Only if disruption to others is very high	If nothing in Category 2 available and only if disruption to others is extreme	Never	Never
Hyperactivity***	Low to medium frequency; low to medium severity	High frequency and severity (extreme disruptiveness, intractability)	Very high frequency and severity (extreme disruptiveness, intractability) and if nothing in Category 2 available	Never	Never
Mannerisms	Low to high frequency; low to high severity	Never	Never	Never	Never
Mildly inappropriate	Low to high frequency; low to high severity	Never	Never	Never	Never
Neurotic**	Low to medium frequency; low severity	Medium to high frequency, medium to high severity	Medium to high frequency and severity, and if nothing in Category 2 available	Never	Never

	Category of service				
	1	2	3	4	5
	General residential or day service with external consultation*	Temporary (less than 90=day) admission to specialized community residence or general-hospital psychiatric facility	Temporary (less than 180=day) admission to psychiatric hospital or special Facility unit	Longer-term admission to specialized community residence or general-hospital psychiatric facility	Longer-term admission to psychiatric hospital or special Facility unit
Nonconformity	Low to medium frequency; low to medium severity	Medium to high frequency and severity; high disruptiveness, intractability	Very high frequency and severity, (extreme disruptiveness, intractability) and if nothing in Category 2 available	If Category 2 has been inadequate; severe intractability of behavior	If Categories 2, 3, or 4 have been inadequate (severe intractability of behavior)
Psychotic**	Low frequency; low severity	Medium to high frequency; medium to high severity	Very high frequency and severity, or medium to high severity and nothing in Category 2 is available	If Category 2 has been inadequate	If Categories 2, 3, or 4 have been inadequate
Withdrawal	Low to medium frequency; low to medium severity	High severity and intractability	Very high severity (intractability), and if nothing in Category 2 available	Never	Never

NOTES: The types of problems are described briefly in Appendix I. The meaning of the terms "low," "medium," "high," and "very high" must be defined by guidelines in each case.

* Consultation usually, but not alway, psychological or psychiatric.
** Psychiatric consultation or admission to psychiatric program may be particularly appropriate.
*** Medical consultation may be particularly appropriate.

RECOMMENDATIONS

1. *The Ministry of Community and Social Services should, as part of its Five Year Plan, encourage and fund in each of the next five years approximately 35-40 residential places that specialize in dealing with developmentally handicapped persons who are behaviorally/emotionally disturbed. The projects should be small(two-to-eight beds), and should be located primarily in areas currently without such residences.*

2. *Persons with behavior-management training should be available to agencies and working groups to act as consultants in the selection of residential settings and in the design of programs for the behaviorally/emotionally disturbed..*

3. *Although, where possible, residences should utilize MCSS funded behavior management programs or Schedule I resources for behavior management programs, this will not always be possible, and for residences that regularly require the services of consultants in behavior management and psychiatry, funds should be built into the base budget. For others, funds can be made available through a special-needs application.*

4a. *The IPP training program should undertake to ensure that all residential staff are sufficiently trained in the principles and techniques of counseling and behavior management so that they can participate effectively in designing and carrying out programs for behaviorally/emotionally disturbed residents with the guidance of a behavior-management or psychiatric consultant. In some situations, where specific individuals are identified, special needs funds may be used.*

4b. *The staff of specialized programs should be skilled in the analysis of and programming for behavioral/emotional problems, including behavior management, crisis intervention skills, emergency medical skills, and physical protection and restraint methods. It should be possible for such specialized programs to have some one time start-up funds which can be used for the provision of essential staff training prior to the admission of residents. Special needs funds may also be used on an on-going basis, if the criteria for that program is met.*

5. *The support services review which is currently underway should examine means by which a corps of support persons not attached to a particular residential program and skilled in behavior-management could be made available to assist, on an intensive but short-term basis, with the implementation of behavior-management programs. Guidelines for the use of such resources should be developed.*

6. *The staff of day programs should participate in the development and, when appropriate, the implementation of behavior-management programs for their clients who are also in residential programs.*

7. *In the absence of an urgent condition outlined in this chapter, a client who displays problem behavior should not be transferred from his or her residence. Rather, a suitable program should be introduced to a resident's current living environment, using the assistance of consultants and, if necessary, the addition of temporary staff. A thorough behavioral analysis of the resident in his current environment should be undertaken in conjunction with a consultant on behavioral/emotional problems before a transfer to a more specialized, intensive program is made. If admission to a specialized program is necessary, a contract should specify the goals to be achieved, the projected time involved, and the willingness of the referring program to take the resident back when the goals of the contract have been achieved.*

8. *As part of the design of any individual program, consultants and staff should undertake a thorough analysis of the physical, social, physiological, and cognitive environments in order to identify factors that may be precipitating or maintaining the problem behavior.*

9. *The Ministry of Community and Social Services and the Ministry of Health should agree on the respective responsibilities of each Ministry in this area, and should jointly prepare guidelines reflecting current professional opinion regarding the conditions and circumstances under which use of each of the levels of specialized programming is suggestd.*

10. *The Ministry of Community and Social Services should undertake discussions with the Ministry of Colleges and Universities to ensure that, in the longer run, training programs relevant to service behaviorally/emotionally disturbed developmentally handicapped persons are available at both the community college and the university level.*

11. *Contingent electric shock and confinement should not be employed in community programs. Excepting DRO, other techniques designed to reduce the frequency of behavior should be implemented only in accord with a set of standards for the use of behavioral modification and related procedures appropriate to community settings. Such a set of standards is currently being developed using the 1978 Facilities Standards as a starting point.*

CHAPTER X RESIDENTIAL SERVICES FOR SENSORY IMPAIRED PERSONS

The combination of a sensory handicap - vision and/or hearing impairment - with a developmental handicap can be devastating for the development of a child or adult and presents a tremendous challenge to workers in both special disabilities and mental retardation. In the past, deliverers of services to the blind and the hearing-impaired have tended to view the group labeled retarded as outside their purview. Similarly, the special needs imposed by vision and hearing losses on the developmentally handicapped have only recently begun to gain attention and appropriate services.

ISSUES

Three major issues are associated with present attempts to deliver adequate residential services to the developmentally handicapped who are also sensorially impaired:

1. The data base necessary for planning services for this group requires improvement.
2. The lack of available expertise in the area has hindered the development of adequate programs to meet these clients' special needs.

BACKGROUND

The Client Group

The term "sensory-impaired" is defined as having impairments ranging from profound hearing loss or total blindness to mild and suspected but undefined hearing or vision loss to varying combinations of impairments in both senses.

Any sensory loss, visual or auditory, deeply influences social and personality development. Blindness and deafness intensify and exaggerate the developmental delays associated with retardation because they sharply reduce the amount of stimulation and information available to the individual, often causing or aggravating communication disorders. Thus, they tend to mask capacity. One result is frequent errors of diagnosis, with the level of retardation being assessed as more severe than it is. (This problem is especially difficult with young children. For example, many Rubella Syndrome infants in the past were diagnosed as severely or profoundly retarded, institutionalized at an early age, and given inadequate stimulation and training. Today we know that early, intensive intervention might have allowed these children to reveal a much lesser degree of developmental handicap.)

The communications difficulties of a sensory handicap can also cause deep depression and withdrawal, which, in turn, exacerbate developmental problems and may further lead to mistaken assessments of severe or profound retardation.

Determining appropriate programming for the developmentally handicapped who are also deaf or blind presents obvious problems. Yet not providing early intervention appears to risk either extreme withdrawal or self-abusive behavior that leads to the use of restraints, medication, and seclusion as management techniques.

Fewer generalizations can be made about the nature and results of deaf-blindness* than about blindness or deafness alone or in combination with a developmental handicap. Individual responses vary, and the sequence of onset of sensory losses can create considerable differences. Moreover, the difficulty of distinguishing the effects of a dual sensory handicap from the emotional response to multisensory deprivation, particularly in the case of a child, calls into question many diagnoses of mental retardation among the deaf-blind. All we know with certainty is that early intervention can dramatically offset the isolation of the individual from the world around him.

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* The CNIB classifies persons as deaf-blind: (1) when the hearing loss is "severe" or "profound" and when the visual impairment is within the terms of "legal blindness"; or (2) in the case of children, when a combination of substantial hearing and visual loss causes extreme difficulty in learning.

The incidence of vision and/or hearing impairment with mental retardation is difficult to determine, but prevalence data indicate that the client group is a significant portion of Ontario's developmentally handicapped. In the Schedule I Facilities, in 1980, 32 per cent of the residents (1845 individuals) were vision- and/or hearing-impaired; in the Schedule II Facilities, it was 42.3 per cent (495 individuals).

Overall data for the province are more difficult to obtain, especially for the vision-impaired developmentally handicapped. For the hearing-impaired, an incidence rate of 10 per cent suggests some 7500 people with some degree of hearing loss and a developmental handicap. As for the deaf-blind, the Canadian National Institute for the Blind (CNIB) estimates Ontario has about 500, of whom 300 are residents of the Facilities.

Service Development to Date

In General

Throughout the Western world, most residential services for blind and/or deaf retarded children and adults have, for many decades, followed the large institutioal model. Tremendous advances have been made in the rehabilitation and education of the sensory-impaired in recent years, as they have in the field of mental retardation, but the two have not often been combined. Efforts to deinstitutionalize the mentally handicapped have led to the extensive development of community residential services for mildly and moderately retarded individuals, but relatively few services for multihandicapped people.

A few exceptions exist. In Britain and the United States, the development of specialized residential services has been gaining considerable attention. In the deinstitutionalization of New York State's huge Willowbrook facility, for example, community residences for the blind developmentally handicapped was a priority.

In Ontario

In 1975, only 48 of the 896 severely vision-impaired residents of the Schedule I and II Facilities were involved in a special program, and most of the totally blind were without programming of any kind. Some major improvements have been made since then. The four largest Facilities have established ten special units that have had some dramatic successes, although the majority of the Facilities' 2340 sensory-impaired residents are not in these units. One half of the sensory-impaired children and approximately one-third of the adults in the Schedule II Facilities participate in up to five hours per week of special programming.

Community-based services for this client group are also quite scarce. Some residential programs will, on occasion, accept a single sensory-impaired client, but few specialized programs exist. For hearing-impaired developmentally handicapped children, there are approximately 40 beds in community settings. For vision-impaired children, there are 13 places (of which eight are at a residential school). For deaf-blind children, there are 51 places (of which 43 are at a residential school). Service for adults is at about the same level. Community residential places are limited to fewer than 50 beds for the hearing-impaired and approximately 30 beds (of which 20 are semi-institutional) for the vision-impaired. There are no specialized community-residence spaces for deaf-blind adults. (See Appendix 6 for details of available service.)

Hopeful Signs for Service Development

Although Ontario is at present providing relatively few specialized residential services for the developmentally handicapped who are sensory-impaired, the constraints on providing service are being lifted by a number of recent changes:

1. The early years of the community-living movement emphasized getting mildly handicapped persons out of institutions. Now that the majority of these individuals have been settled in the community, more attention can be paid to creating small, family-like settings and normalized environments for the more severely handicapped, including the multiple handicapped.
2. The 97:3-per-cent formula for funding accommodations for children has made it possible for more agencies to begin providing residential services for this group.
3. The numbers of multihandicapped vision- and hearing-impaired children are increasing (because of the high survival rate of premature babies and the sophisticated infant care now available). Thus, it is becoming possible to design practical service catchment areas for these groups.
4. The integration and normalization movement has changed attitudes toward serving the blind and shown that the academically normal blind person does not need segregated services. Hence, the multihandicapped and blind slow-learners may receive an increasing proportion of the resources of agencies specializing in services to the blind.
5. Groups serving the deaf are beginning a similar movement away from exclusive residences. The Ontario Community Centre for the Deaf and a few others will now admit deaf children or adults with an additional problem, such as a developmental handicap.
6. Expertise in the kinds of programming necessary to assist sensory-impaired developmentally handicapped persons to achieve their maximum potential is gradually being developed in the Facilities' special units and certain community agencies. Outreach, formal or informal, can go from these existing programs to potential community-service providers.

In summary, interest in the overlapping fields of developmental handicaps and sensory disability is growing. There is now a need for policy and program guidelines to ensure that development takes place in a planned, coherent fashion.

DISCUSSION OF ISSUES

The provision of services specifically geared to clients who are both developmentally and sensorially handicapped is such a new field that a number of additional background issues must be clarifed.

Integration and Segregation

Planning services for the multihandicapped raises questions about two different kinds of integration. Should sensory-impaired clients be integrated with their sighted and hearing peers or should they be segregated in specialized residential services? And should the vision-impaired be mixed with the hearing-impaired?

The Facilities' special units have chosen the segregated approach as a means of promoting interaction between residential counselors and residents, increasing residents' privacy and individual programming, making environmental improvements and adaptations,and providing a base for development of staff expertise. Some community-based programs may use a similar rationale. Certainly multihandicapped individuals who have not had the benefits of adequate intervention need an intense supportive environment with staff who have specialized skills and back-up to assist them.

In addition, less specialized services are also required for some individuals who are ready for integration with hearing or sighted people in less structured programs.

One key principle on which there is general agreement is that hearing-impaired and vision-impaired clients should not be mixed in the same home.

The Lack of a Data Base

The provision of service to this client group tends to get caught in a cycle of inertia. Since many agency and service planners are unaware that the population exists, they make no attempt to identify it. Consequently, no specific data are available, no plans are made, and few if any programs meet these people's needs. In the absence of programs, they remain invisible.

One way to break this cycle is to collect specific information to create awareness. In many cases, the data exist, but the sensory-impaired have not been broken out of the more general "multihandicapped" category. Neither has the information been aggregated and analyzed to enable planning for this client group.

Analysis of detailed service-needs, region by region across the province, should identify the numbers of blind and deaf multihandicapped people who require residential and support services in order to continue to remain in their communities. Much could be learned by analyzing existing data on the sensory-impaired residents of the Facilities, Homes for Special Care, childrens' nursing homes, and other institutions, as well the clients of community agencies, schools, and the major service-providers in the vision-and hearing-care fields, such as CNIB (including its Deaf/Blind Intervenor Service), the Canadian Hearing Society, and the Ontario Mission for the Deaf.

Staff Training

Professional services for the multihandicapped - whether the impairments are visual, aural, multisensory, or developmental - are very much in their infancy. Preparation of professional personnel usually takes the form of the development of competency to work with single-disability categories, such as "the retarded," the blind, or the deaf. Training programs for teachers of the multihandicapped are extremely limited: W. Ross MacDonald School established a three-year certification program in 1976 to certify teachers of deaf-blind children, but no university program exists in Ontario for training persons to work with the blind developmentally handicapped.* Training programs for psychologists, psychiatrists, and social workers offer few opportunities to specialize in serving the developmentally handicapped and virtually none for working with the retarded who are also sensory-impaired. Residential counselors with Mental Retardation Counsellor (MRC) or Early Childhood Education training have had, in some cases, short or introductory courses in the field of sensory-impairment, but no community college systematically provides courses by, for example, CNIB staff.

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* The only one in Canada is at the University of British Columbia.

Specialty training beyond the MRC, particularly for teachers, should be discussed with the Ministry of Education. The need for specialist[*] is made more pressing with the phasing in of Bill 82 by September 1985.

TYPES OF RESIDENTIAL PROGRAMS

For minority of developmentally handicapped people who are sensorially-impared, any of the community-based residential models described in Chapter V, including specialized family care, would be functional. However, the complex nature of the special needs created by dual handicaps makes the majority of this client group "hard-to-serve." Given the large number of children and adults with these handicaps in the Facilities as well as those living at home for whom institutionalization is the only residential alternative, it is proposed that the Ministry plan for the development of 15 to 20 places annually in specialized group homes, or converted semispecialized homes for this population. Development and conversion of such homes would be within the scope the Ministry's Five Year Plan. The residential needs of deaf-blind individuals would have to be evaluated, on a region-by-region basis, in liaison with case managers from the MCSS Deaf-Blind Intervenor Service.

Both the specialized and semispecialized residential programs described below incorporate intensive, specialized staffing. Because of the nature of sensory impairments and their tendency to isolate the person from others and from the world around them, the vision- or hearing-impaired person who is also developmentally handicapped needs a great deal of one-on-one intervention and appropriate stimulation to encourage interpretation of his or her environment. (Appendix 6 presents a list of the needs of these clients.)

Model One: Fully Specialized Community Group Home for the Sensory-Impaired

The fully specialized community group home would be an adaptation of Model D, specialized family care, or Model F, shift-staffed residences. It would be designed for exclusive accommodation of blind multihandicapped persons, deaf multihandicapped persons, or deaf-blind persons. Its main features would be an intensive training and habilitation program and specialized staff with back-up and ongoing support from consultants to the program.

Following the principles recommended in previous sections of this paper, the preferred number of residents per home is four, and every effort should be made to maintain small, family-like settings.

These homes would not, in most cases, be permanent placements for clients but settings designed to help them develop to the point of being able to move to the semistructured setting (see page 66) after three or four years. Each of the Facility special units should, therefore, be linked with one of these specialized group homes to ensure movement from the former's highly structured situation to the more integrated, normalized environment provided by the community setting.

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[*] The Southwest, Central, and Southeast Regions already have one group home each for deaf multihandicapped adults.

In establishing the service, priority should go to homes for multihandicapped children, for whom the impact of early intervention is enormous. Deaf-blind young adults graduating from W. Ross MacDonald school should also be given priority.

In future years, as the Facilities begin to develop more community group homes, it may be necessary to provide incentives to design a portion of their spaces for the sensory-impaired client group.

Program Content

The intensive habilitation program of the fully specialized community group home should be aimed at teaching daily living skills with effective individual program plans developed for each resident. The range of available services and programs should include assessments, sensory-awareness training, mobility and orientation training, language learning and communication, special equipment, life-skills training, exercise, and remedial education (see Appendix 6 for details).

Staffing

It is difficult to speak of academic qualifications necessary for staff to work with the hearing- or vision-impaired developmentally handicapped in residential services.* The experience of the handful of specialized community group homes in Ontario, however, suggests that staffing skills and attitudes should include: (1) experience with the deaf or blind, perhaps acquired through educational programs or volunteer work; (2) willingness to attend in-service training workshops, conferences, courses or signing, and so on; (3) an interest in working with the multihandicapped; and (4) the knowledge of developmental handicaps normally acquired through completion of a recognized course of study.

The availability of specialized professional consultants and external support staff is essential (see Chapter XII for a fuller discussion). Ideally, a specialized home serving the blind or hearing-impaired developmentally handicapped should have access to a number of the following specialists and supports:

1. A psychologist with rehabilitation-team experience.
2. Mobility instructors (for the blind).
3. An occupational therapist experienced in learning disabilities and perceptual handicaps.
4. Special education teachers or tutors for remedial education.
5. Volunteer readers from CNIB (preferably a retired teacher).
6. A recreationist with training in working with the disabled.
7. A communication specialist (for example, a speech pathologist to develop remedial communication skills with the deaf).
8. Periodic assessment services, particularly audiological and otolaryngological (ENT) for the hearing-impaired.
9. Presence of an adult deaf community in its vicinity. Although the developmentally handicapped might face problems of acceptance here, it would be an asset for many and would ensure the presence of some support services.

These supports would, in some cases, require purchase-of-service arrangements, Vocational Rehabilitation Services support, or Special Needs funding. In other cases, voluntary cooperation with community service organizations would be sufficient.

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* Staff as it is used here would pertain either to shift-staffed or parent-model group homes.

Semispecialized Community Group Home for the Sensory-Impaired

The semispecialized program would house sensory-impaired clients in existing group homes for the hearing and sighted developmentally handicapped. The main features of such homes should be program modifications as outlined in Table 4, some specialization of staff, ongoing support and back-up from specialized consultants, and a staff-to-resident ratio lower than the average group home's.

As with the specialized program, the number of residents would be small. Location and physical features of the home would be factors in its selection for serving the sensory-impaired.

Clients should not have to travel hundreds of miles from their home communities to obtain residential services of this semispecialized type. Two to four group homes per region should be able to accommodate blind multihandicapped adults, and a similar number of deaf multihandicapped adults.* The need for group homes for children presently living with their families would require careful evaluation; priority should go to children in the Facilities. The possibility of a joint project with the Ministry of Education to provide accommodation close to W. Ross MacDonald School should be investigated.

Flow-through of residents to less-structured residential settings would be desirable; however, it is difficult to project the percentage turnover.

Program Content

Specialized programming would be somewhat less intense in this setting than in the fully specialized home, but some of its features should be incorporated as necessary to meet the clients' individual needs. Table 4 shows the nature of the modifications required to adapt existing community residences to hearing- or vision-impaired people.

Staffing

Before an existing group home could undertake serving a sensory-impaired client, it would have to employ one or more persons with specialized skills, such as those required for the fully specialized home, and to develop a training program for existing staff with the help of consultants from agencies in the special-disabilities fields (for example, CNIB or the Canadian Hearing Society). As well, an increased staff-to-client ratio would be required; the number would depend on the number of multihandicapped clients to be admitted and their special needs, such as assistance with transportation and mobility in the community.

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* A small number of such group homes now exist in three regions.

TABLE 4 ADAPTING COMMUNITY RESIDENTIAL SERVICES FOR THE SENSORY - IMPAIRED

Population	Program Modification	
	For hearing-impaired clients	For vision-impaired clients
Developmentally handicapped individuals with mild hearing impairment or partial vision.	Orientation of residence staff to hearing impairment.	Orientation to blindness training and residential staff.
	Client use of hearing aid.	Orientation and mobility training for clients including low-vision training; use of low-vision aids by clients.
	Appropriate seating arrangements.	Physical adaptations such as brightly colored markers, visual cues, safety features.
Developmentally handicapped individuals with moderate hearing impairment or guiding vision (legally blind).	Orientation of staff to hearing impairment.	Orientation to blindness: training and ongoing support for staff.
	Client use of hearing aid and other devices.	Orientation and mobility training for clients including caning, use of vision cues, etc.
	Physical safety features such as visual fire alarms.	Physical safety features such as stair gates, door latches.
	Back-up resource staff.	Back-up resource staff.

Population	Program Modification	
	For hearing-impaired clients	For vision-impaired clients
Developmentally handicapped individuals with severe to profound hearing loss or no vision (legally blind).	Orientation of staff to hearing impairment.	Orientation of staff to blindness: training and ongoing support for staff.
	Client use of hearing aid and other devices as appropriate.	Orientation and mobility training for clients.
	Specialized staff to work with clients on ongoing basis.	Specialized staff to work with clients on ongoing basis.
	Client-staff use of sign language.	Physical safety features such as stair gates, door latches.
	Physical safety features such as visual fire alarms.	

NOTE: Juxtaposition of the hearing-impaired and the vision-impaired on this chart is not to be interpreted as a recommendation to these clients in a single group home. Rather, it is recommended that separate residences be developed.

RECOMMENDATIONS

1. *In each of the next five years the Ministry should fund the development of approximately 15 to 20 residential places to accommodate developmentally handicapped persons with sensory impairments.*
2. *Guidelines, elaborating the program content described in this chapter, should be developed for these residential programs to assist Regional and Area offices in the development of services to those persons.*
3. *Ministry consultants on the hearing-impaired and vision-handicapped should be made available provincially to work with service providers in community, residential, and day programs on program modifications and staff training to meet the special needs of the sensory-impaired client group.*
4. *The Ministry should approach District Working Groups concerning the analysis of available data and data requirements on the needs of the sensory-impaired developmentally handicapped.*
5. *Regional plans should incorporate consideration of the special needs of this client group to ensure improved residential services.*
6. *In the development of more community-based residential alternatives for multihandicapped persons, the Ministry should foster cooperation and joint planning among service-providers to the developmentally handicapped and the vision- and hearing-impaired to ensure that expertise in the special-disability fields be drawn upon in the planning of residential services.*
7. *The Ministry of Community and Social Services should undertake discussions with the Ministry of Education and the Ministry of Colleges and Universities concerning the training of qualified personnel in the fields of developmental handicaps and sensory impairment.*
8. *It should be possible for such specialized programs to have some one time start-up funds which can be used for the provision of essential staff training prior to the admission of residents. Special needs funds may also be used on an on-going basis, if the criteria for that program are met.*

CHAPTER XI RESIDENTIAL SERVICES FOR SEVERELY AND PROFOUNDLY RETARDED AND MULTIHANDICAPPED PERSONS

During the last several years, it has become increasingly clear that the same principles of community residential service delivery that apply to less impaired developmentally handicapped persons also apply to severely and profoundly handicapped persons. Virtually all can live in heterogeneous integrated community settings.

The view that active programming can benefit seriously handicapped persons is only gradually replacing the view that such interventions will achieve little or nothing. The label of severely or profoundly retarded is usually awarded in early infancy, and the diagnosis itself can still be a major obstacle to developmental growth because many people - professionals and nonprofessionals - interpret it as synonymous with hopelessness rather than as an identification of obstacles to be overcome. This prevailing attitude, combined with the objective severity of the handicapping conditions and the scarcity of both day and residential programs, has led many parents to seek admission to Schedule I or II Facilities for their severely or profoundly handicapped children despite the clear benefits of community placements.

Because this client group in general, and multihandicapped children in particular, constitute a major source of pressure on institutions, prevention of institutionalization of children will be impossible unless more community residential services are developed for the multihandicapped.

ISSUES

At the present time, there are some gaps in the residential and day services available to serve severely and profoundly retarded persons, particularly those who are multiply handicapped. The five year plan provides the opportunity for expansion of services to this group of people.

BACKGROUND

The Client Group

No single definition can adequately describe the heterogeneous group identified as severely and profoundly retarded and/or multihandicapped; however, the following can provide a reference point for discussion:

The severely handicapped individual is one whose ability to provide for his or her own basic life-sustaining and safety needs is so limited, relative to the proficiency expected on the basis of chronological age, that it could pose a serious threat to his or her survival.*

It may also be useful to note that the classification scheme described in Chapter V and used elsewhere in this paper would list such clients as very or extremely dependent.

Although severe or profound retardation implies a substantial degree of intellectual impairment, as well as dependence, it does not mean that these individuals are unable to learn. Given effective training, the less severely disabled among them, particularly those who do not have major physical or sensory impairments, can acquire substantial productivity in a vocational setting as well as considerable proficiency in self-care skills, including dressing, eating, and personal hygiene, and some social, domestic, and community-usage skills. Even most of the more disabled can learn to participate in meeting some of their own needs, to communicate some of their needs and feelings, and to expand their awareness of their world, and their behavioral repertoire in dealing with it, as well as their enjoyment of it.

Complicating Physical and Sensory Handicaps

A substantial proportion of persons with severe developmental handicaps also have physical or sensory handicaps, most commonly spastic or athetoid forms of cerebral palsy, spina bifida, hydrocephalus, paraplegia or quadriplegia, and epileptic seizures. (Appendix 14 outlines these problems in more detail, and Appendix 15describes the effects of one or more such problems on three individuals.)

Many of these conditions tend to lead to additional complications, developmental or medical. Complex seizure disorders may require treatment with heavy doses of anticonvulsants, which further impair awareness. Insufficient movement may create a pooling of infection causing secretions in the lungs. Persons who lie on their backs for prolonged periods are prone to decreased vitality of the lungs, caused by the pressure of gravity on the chest. Not using joints and muscles or lying in poor positions can lead to the development of additional orthopedic deformities. The correction of deformities may require extensive surgery and medical management, which increase time spent in unstimulating environments, thus interfering with learning opportunities.

Some severely handicapped individuals are commonly referred to as "medically fragile." Recent expert opinion suggests that this subgroup is a smaller group than had previously been thought, but it includes at least persons who: (1) are at risk because of their respiratory status; (2) have difficult-to-control seizures (including those who may experience status epilepticus); (3) are orthopedically at risk, such as persons with osteoporosis. These people need round-the-clock nursing care, a requirement that might seem to bar them from placement in community residences. The "medically fragile" label need not, however, last forever. Good physical therapy, proper positioning, increased quality of respiration, and continued medical investigations leading to better seizure control can eventually decrease the nursing required. Meanwhile, even 24-hour care can often be provided in small, residential settings by external support staff (as described in Chapters V and XII). (For example, nurses employed by an external program could provide service to an individual as long as it was needed, then move on to other clients in different residences.)

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* Baker, D.B., "Severely Handicapped: Toward an inclusive definition," AAESPH Review, 1979, 4(1), p.60.

Service Development To Date

In General

The concept of normalization, as it emerged in the late 1960s and eary 1970s, led to the development of models of care for severely and profoundly retarded and multi-handicapped people outside large, isolated institutions. One of the first steps in moving this client group out of institutions was taken in Omaha, Nebraska. The most "medically fragile" and physically impaired children from a large state institution were transferred to a Developmental Maximization Unit, set up in a wing of the local general hospital. Many children improved in health and some moved on to group home settings. During the last ten years more and more severely disabled and dependent persons have been moved to normal residential settings in both Canada and the United States. Several years ago, Alberta transferred a number of people to specially built homes in the suburbs of Edmonton and demonstrated that they thrived in more normalized surroundings. In early 1982, Newfoundland institutions moved some of their most dependent youngsters (several on gastrostomy tube feeding routines) to a small unit of the Springdale General Hospital. Over the next eight months the children learned to eat without the tubes; twenty have now moved out of the hospital to group homes since September 1982 and are attending school. Arizona now has over 500 persons labeled severely or profoundly handicapped living in four- to five-bed group homes dispersed throughout the state.

In Ontario

Ontario has an estimated 7000-8000 severely or profoundly retarded and/or multicapped persons; 4000 of them, including over 750 children, live in Schedule I and II Facilities and approximately 1700 in Homes for Special Care.

The first community placements for this client group came in 1978-9 with the opening of three core residences in areas where developmental day programs were available. No expensive, specialized housing was used, a decision whose wisdom was shown by the residences' success and reinforced when Rygiel Home in Hamilton moved some of its most dependent children into regular apartments. The local AMR in Oshawa began to offer alternative family care in the fall of 1981, and it has provide a viable residential option.

DISCUSSION OF ISSUES

Response to Common Objections to Small Residential Settings

The Residential Models Policy Task Force has endorsed the basic principle that residential services for severely or profoundly retarded persons should be available to them in their own community. Such services have two objectives: (1) the provision of a much smaller, more personalized environment than is possible in an institution, and (2) the provision of intensive, individualized programming. It has been demonstrated that such residences' small numbers of people, and the flexible, personalized routines possible in family-like settings enable severely handicapped people to experience the bonding and emotional nurturing that are prerequisites to development.

In the past, the prevailing view was that providing adequate programs for more severely disabled people required bringing them together in large groups geographically separated from the community because:

1. This was the only way to make available the variety of professional services they require.
2. Smaller settings may be organizationally less stable than institutions, many of which are provincially operated.
3. The public would not accept such people in their midst.
4. Health needs require this group to live in institutional settings.

Current evidence indicates, however, that these concerns should no longer deter the provision of community services.

1. Small residences can make available, at similar cost, all the specialist services found in larger settings. They can also provide an equal or higher level of direct-care staffing because they do not require support and maintenance staff (see Chapter VI for more detailed discussion of this point).
2. Organizational stability does not appear to be an issue. The Ministry of Community and Social Services has made a firm commitment to providing residential care to developmentally handicapped people, and that commitment will be honored whether clients are in small or large residential settings.
3. Although some people may respond adversely to the presence of severely and profoundly handicapped persons in their community, such a response is much less likely where small numbers of clients are involved. Two to four handicapped people living in a staffed apartment, townhouse, or detached home have much less impact on the surrounding neighborhood than small institutions of 30 or even eight- to ten-bed group homes.
4. Clearly, management of the severely handicapped requires thorough assessment of individual clients' health-care needs, but this is true no matter what size facility they are accommodated in. Generic health-care services are present in almost all parts of Ontario, and community residential programs can and should use them to the full. For example, they can and should provide registered nurses skilled in dealing with severely handicapped people to supervise resident care and to teach basic nursing skills to the front-line staff.

Staff Training

The multiple learning and behavior deficiencies that characterize the severely and profoundly handicapped mean that considerable one-on-one interaction is necessary in providing them with developmental training associated with the activities of daily living - feeding, dressing, toileting, body postitioning, passive exercising, mobility training, language stimulation, and so on. As agencies take on the provision of services to these clients, there is increasing demand for residential counselors with expertise in meeting their special needs. Individual Program Planning will be an essential component of practice, and staff training in IPPs should pay special attention to this client group.

Another area of concern is availability of skilled personnel at the professional level. Redeployment of facilities' staff to community services would help in reducing shortages of qualified professionals.

A recent report on assessment services, prepared by external consultants, identified province-wide shortages in five professions: psychology, speech pathology, physiotherapy, occupational therapy, and psychiatry. Recommendations are that the Ministry promote the placement of student interns in assessment services for the developmentally handicapped; such experiences would introduce young professionals in these disciplines to the field of developmental handicaps and interest them in serving our client group. Consideration should be given to arranging internships in community programs for severely and profoundly retarded and multihandicapped people, such as the children's core residences and Rygiel Home.

TYPES OF RESIDENTIAL PROGRAMS:

Almost all of the models of community-based residential services described in Chapter V are appropriate for the severely and profoundly retarded individual. The parental home and alternative family care models require that there be considerable external support services in the community. Where such services have not been developed, specialized models are necessary. These should offer a homelike environment in a house, townhouse, or apartment with a range of physical, emotional, social and educational supports.

Specialized Community Home for the Profoundly Retarded Multihandicapped

The specialized community home would be designed to accommodate from two to six extremely dependent multihandicapped individuals with relatively specialized needs in environment, staffing, and program content.

Environment

The residence should be located in an established residential area. The entire environment should promote positive experiences, allow for privacy and choice, and encourage functional independence regardless of the severity of residents' disabilities.

Accessibility

Making regular housing barrier-free may require some modifications. Buildings must have street-level or ramped entrances; apartments require either a ground-floor location or access by elevator. Doorways must be wide enough to accommodate custom-designed wheelchairs, and at least some windows should be low enough to allow residents to keep in touch with their surroundings. Other adaptations include lowered light switches, sinks, and cupboards and bathroom aids, such as grab bars.

Stimulation

The size of the home is critical to providing a stimulating environment for severely disabled people. Apartments or single-family houses are most likely to offer an environment that fosters close, family-like relationships and maximizes opportunities for growth-promoting experiences, which contribute to increased independence.

The creative use of music, records, tape recorders, colors and textures, food, plants, and pets in the home can provide the stimulation that very dependent people require.

Space may need to be allocated for one-to-one instruction.

Staffing

Direct Care Staff. Staff need to be both capable of adapting to working with the multihandicapped and committed to teaching independent living skills to these clients. Caregivers should have - and be free to use -intuition and creative talents to produce a normalized environment with high expectations for success. They also need to be able to implement a prescribed developmental program, to engage in therapeutic handling, and to interpret communication from nonverbal, physically helpless persons, as well as to anticipate their needs. Movement and exercise are vitally important to the maintenance of good lung function and digestion and the increase of fine and gross motor skills; consequently, staff should have training in lifting, positioning, and the use of functional seating. In addition, knowledge of behavior-management techniques and fire and safety measures are essential.

Professional Consultants. Any residence serving highly dependent clients must have access to the expertise of skilled professionals capable of dealing with individual problems and providing back-up crisis intervention. These may include physicians, nurses, physiotherapists, occupational therapists, dieticians, and psychologists.

All staff members may not require all of the skills outlined, but in the small (two- to four-bed) settings being recommended, all caregivers should have many skills and be able to understand clients' needs in order to provide meaningful input into individual program planning and implementation. Moreover, because the provision of developmental services to this client group is in its early stages and new approaches are appearing regularly, it is essential that staff be willing to keep up to date with innovations. Finally, they must be confident that in cases of emergency or crisis, counseling and assistance are available.

Program Content

The purpose of the program in a community residence is to maximize opportunities for the severely handicapped person to learn through pleasurable and stimulating experiences. For this client group, the essential goal is for each person to gain some control over his or her physical and social world, beginning with self-awareness and followed by increased complexity of motor behavior and by improved communication. Key elements in the overall program would be:

1. Development of sensorimotor skills. A systematic developmental program for each client must be planned and carried out with the help of such support personnel as physical and occupational therapists. This will usually involve the use of appropriate handling procedures, the provision of functional seating, training in ambulation, and making available in the correct sequence activities appropriate for muscle and coordination development.
2. Some degree of more independent existence is always possible for profoundly and multihandicapped individuals. Self-care skills should be taught, using as much time and effort as necessary to accomplish any given objective.
3. Development of functional communication. Any approximation of normalization is largely dependent on the ability to communicate. Such training should be given great emphasis.
4. Reduction of maladaptive behavior. Many multihandicapped individuals engage in stereotypic or other inappropriate social behavior that disturbs others, and, more significantly, some also injure themselves. In these instances, individual program plans must incorporate behavior-management strategies that are carried out through a mediator model and/or direct intervention by appropriate personnel. Individuals with severe behavior problems may require a specialized residential program of the type described in Chapter IX.

5. Health maintenance. The program should arrange for periodic health assessments, including vision and auditory checks; these must involve professionals who have experience with difficult-to-test clients. Nutrition and seizure control are other important areas in preventive health care.
6. Recreation and leisure. Activities such as swimming can meet needs for both social and physical development. The use of community parks and playgrounds and other local facilities should not be overlooked.
7. Day programs. Clients should have special life skills or day programs, designed to serve their needs. Such programs should only take place in the residence when no alternatives are available.

Appendix 16 details areas of program emphasis for profoundly retarded persons.

Community Home for the Severely Retarded

A specialized community home designed to accommodate severely retarded persons would be similar to that described above, but its focus would be on serving individuals whose potential for independent functioning is greater than profoundly retarded people's.

Environmental and staffing considerations would be essentially the same as for the program serving less capable individuals, although some of its environmental modifications, such as wheelchair accessibility, may not be necessary, depending on specific clients' physical handicaps. The emphasis would be on creating a homelike atmosphere fostering learning experiences that lead to increased independence. It would be expected that as clients gained in independent living skills they would move on to regular group homes or that the intensity of staffing in the home could be reduced.

Program Content

A program geared to the needs of severely retarded residents would incorporate the following key areas:

1. Teaching of self-care skills. Competence in dressing, eating, personal hygiene, and basic housekeeping are important goals for clients and should form a major part of the overall residence program.
2. Development of functional language. The development of language facilitates the attainment of many other educational objectives for children and makes possible higher functioning levels for adults.
3. Reduction of maladaptive behavior. Aggressive behavior tends to occur more frequently among this client group than among profoundly retarded persons. A number of residents may require considerable use of external consultants and other support services; temporary placement in a residential program specializing in behavior management (see Chapter IX) may occasionally be required.
4. Health care. The program should incorporate preventive health care measures, including periodic assessments of vision and hearing.
5. Recreation and leisure. Social activities, including field trips and the use of community recreational facilities, are important ways of helping clients improve their social behavior by giving them a chance to observe "normal" people and activities and practice imitating them.
6. Day programs. It should not be necessary to conduct day programs in the residential setting for severely retarded people. Children should be in developmental centers or schools, and adults in life skills or vocational programs.

Given the importance of respite services in preventing institutionalization of handicapped children living at home, it is strongly advised that both these models of specialized community homes include respite care in their programs.

RECOMMENDATIONS

The following recommendations for the expansion of community residential services for severely and profoundly retarded and multihandicapped persons are predicated upon the development of support services.

1. *During each of the next five years, the Ministry of Community and Social Services should fund approximately 30 to 35 residential places in the province that correspond to the specialized residential programs described in this chapter for profoundly and severely retarded and multihandicapped persons.*
2. *In order to increase the availability of qualified personnel:*
   - *(a) The ministry's Individual Program Planning project should incorporate in its proposed training special attention to the needs of this client group.*
   - *(b) The Individual Program Planning project should also include training packages for parents of severely and profoundly retarded children to assist them in caring for their children.*
   - *(c) The MCSS should approach the Ministry of Colleges and Universities regarding incorporation, into core curriculum guidelines issued to community college programs in mental retardation and early childhood education, appropriate content on serving severely and profoundly retarded and multihandicapped persons in community settings. In addition, MCSS should initiate discussions designed to increase the availability of trained professionals such as physiotherapists, speech therapists who are able to work effectively with severely and profoundly impaired and/or multihandicapped individuals.*
   - *(d) It should be possible for such specialized programs to have some one time start-up funds which can be used for the provision of essential staff training prior to the admission of residents. Special needs funds may also be used on an on-going basis, if the criteria for that program are met.*

CHAPTER XII COORDINATION WITH OTHER SERVICES

The residential models described in Chapters V and VII to XI are designed to make it easier to tailor available services to individual needs. Since these needs change over time, the most cost-effective manner of achieving the required flexibility is to meet an increasing proportion of them through support services not directly connected with a specific residence. Level Three of the funding formula proposed in Chapter VI would make it possible to provide and withdraw such external supports as needed, without disturbing a residence's staffing base.

The Ministry of Community and Social Services already provides a number of relevant support service programs, and an expansion is called for in the Five Year Plan. The Ministry is at present reviewing several of these programs, including the Family Support Worker, the Adult Protective Service Worker, and the Infant Stimulation programs, as well as sheltered workshops. These reviews plus implementation of the policy paper on Individual Program Planning should resolve a number of previously identified issues related to the coordination of services for individuals.

Policy Development is also examining in detail the kinds of support services required to implement the models described in the previous chapters. Some preliminary suggestions can be made in the interim.

ISSUE

1. What steps can be taken to ensure the accessibility of existing support services and to increase the availability of those support services that are in short supply?

BACKGROUND

If community residential programs are to use external support systems increasingly and effectively, a number of conditions must exist:

1. Individual program plans must be developed so that staff can pinpoint areas in which they need external assistance.
2. Residential staff must be aware of the support services available and how to obtain them.
3. Residential programs must have Special Needs funds with which to purchase external services.
4. Gaps in the availability of resources must be identified and steps taken to fill them.
5. Professionals must have opportunities to gain experience and, if necessary, training, in the application of their skills to developmentally handicapped persons.

TYPE OF EXTERNAL SUPPORT REQUIRED

Successful implementation of all the proposed models of residential care will depend to a great extent on the availability and accessibility of a range of support services, including: (a) specialized professional consultation; (b) external support staff; (c) day programs; and (d) respite care.

Specialized Professional Consultation

In this context, specialized consultants include professionals in the fields of medicine, dentistry, psychiatry, psychology, behavior management, speech therapy, physiotherapy, audiology, gerontology, and so on who can provide consultative assistance, carry out programs, or design programs and supervise their implementation by residence staff and/or external support staff. Some of these services are already funded through OHIP or are provided by MCSS-funded support programs.

Preliminary analyses of the need for such services have already been done in certain communities, through District Working Groups, District Health Councils, or local children's services committees. Other communities should consider a similar step. The identification of which areas are lacking which resources might lead to consideration of such steps as the provision of incentives for relocation and manpower training and/or retraining programs. As alternative accommodations for Schedule I and II Facility residents are developed in the community, much professional support could be provided by redeploying current Facility employees as is being done in Brockville. When services are not available through this mechanism, through OHIP, or through existing MCSS-funded support services, Special Needs funding could be used to purchase support services from agencies or private professionals.

External Support Staff

From time to time, a resident may require some intensive service that is related to an identified need within the residential program but which cannot be met by regular program staff either because they lack the expertise or because provision of such intensive service to one client would result in a significant, detrimental reduction in the level of service provided to other residents. (Such intensive services might include, for example, the temporary provision of a one-on-one behavior management program where a mediator model approach does not seem to be effective.)

The availability of external staff for these services would provide the residential service system with the flexibility to meet the special needs of all clients while minimizing the need to uproot or relocate residents to unfamiliar settings.

Other external support staff are also required to provide advice, assistance, and program coordination to the operators of alternative and specialized family-care homes, as well as to provide service to those adults living semiindependently. Many of these persons are now receiving such services from family-support and adult-protective-service workers.

When Ministry-funded programs cannot provide external support services, they could be obtained on a contractual basis using Special Needs funding.

Day Programs

According to Ministry policy, all persons in residential programs must have some form of regular day activity; this is usually a developmental or school program for children and a life-skills or vocational program for adults who are not employed. There is, however, a shortage of day program resources for the more severely and multiply handicapped, and for persons with sensory impairments, communication difficulties, and behavioral/emotional problems. In addition, some areas of the province have waiting lists for admission to existing programs.

Service coordination, as outlined in the policy paper on Individual Program Planning, is necessary to ensure that day-program and residential-program staff have a shared perception of clients' needs and a common understanding of the manner in which those needs can best be met.

Respite Care

An important component of the proposed parental, alternative, and specialized family-care models (Models A, C, and D) is the availability of relief services. Short-term emergency placement should also be available for residents in all models of care.

Planned Respite Care

The knowledge that respite care will be available for a specific number of days per year may well encourage some parents to maintain their handicapped children at home; it may also aid in the recruitment of alternative family-care home operators.

Some guidelines will need to be developed regarding the use of planned respite care. Among the major determinants of the number of days available per year should probably be the level of the client's disability and the experience of the caregiver.

When the regular caregivers agree, respite care should probably be given in the client's usual home. Such an arrangement would result in the least possible disruption of the resident's routine and permit programming to continue in familiar surroundings. Caregivers could be drawn from the pool of external support staff; in addition, some alternative family-care operators could be recruited solely for the provision of respite care, and existing parent-relief programs could also be used.

Emergency Short-Term Placement

Accommodation in community residences or in Schedule I and II Facilities should be available in the event of emergencies involving either the clients or the operators of residential programs.

RECOMMENDATIONS

A number of actions that will contribute to the development and coordination of support services have already been dealt with in other chapters of this paper (for example, Special Needs funding for adults), in other recent policy papers (such as that on Individual Program Planning), or have been Ministry policy for a number of years (such as the linking of day programs with all new residential programs). In addition:

1. *Local communities should undertake a survey to identify the types of additional support services they require on an ongoing basis.*
2. *MCSS Policy Development should write, by the end of fiscal year 1983-84, a policy paper that reflects the views of knowledgeable persons regarding the support services required for persons with sensory and communication impairments, for the behaviorally/emotionally disturbed, for the severely, profoundly, and multiply handicapped, and for the elderly. The need for various types of respite services should also be covered. These recommendations should serve as the basis for developing additional support services. Some program areas would then require more specific guidelines, elaborating on the policy.*

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APPENDICES

TABLE OF CONTENTS

			PAGE
Appendix	1	The Operation of Community Residential Programs for the Developmentally Handicapped	1
	2	The Group Home Policies of Ontario Municipalities	2
	3	Responsibility for Group Homes	6
	4	Proposed Clarification of the "50/50 Rule" for Admissions to Group Homes for the Developmentally Handicapped	7
	5	Alternative Means of Measuring the Level of Service Required by Individuals in Residential Care	8
	6	An Example of an Instrument for Measuring Levels of Disability	11
	7	Examples of Estimated Costs for Various Models of Residential Care by Level of Disability	33
	8	Needs of the Elderly Retarded	39
	9	Types of Behavioral/Emotional Disturbances among the Developmentally Handicapped: One Approach to Classification	40
	10	Environmental Analysis and Problem Behavior	41
	11	Advantages and Disadvantages of Moving Disturbed/ Disturbing Clients to Specialized Residences	42
	12	Specialized Residential Services Now Available in Ontario for People Who are Sensory-Impaired and Developmentally Handicapped	43
	13	The Needs of Multihandicapped Clients	46
	14	Descriptions of Physical Handicaps Frequently Associated with Profound Retardation	49
	15	Case Histories: Three Profoundly Multihandicapped Persons	54
	16	Areas of Program Emphasis for Profoundly Retarded Persons	56

APPENDIX I

The Operation of Community Residential Programs for the Developmentally Handicapped

	Adults		Children		Children & Adults(Mixed)	
	Homes	Clients	Homes	Clients	Homes	Clients
Associations for the Mentally Retarded	233	1870	26	281	-	-
Other charitable organizations	56	467	13	187	-	-
Children's boarding homes	-	-	(194)[a]	(1475)	-	-
Children's Mental Health Centres	-	-	70	659	-	-
Schedule I Facilities						
Approved Homes	41	101	11	24	15	50
Community residences	5	53	-	-	2	18
Boarding homes[b]	8	11	4	7	1	2
Schedule II Facilities						
Approved Homes	-	-	3	20	1	16
Community residences	1	4	-	-	-	-
Apartments	1	2	6	18	-	-
Individualized settings	-	-	-	-	16	14
Homes for Special Care of Health[c]						
Nursing homes[d]	-	-	-	-	199	1977
Residential homes	154	512	-	-	-	-

---

a Data indicate total number of clients, who may be developmentally handicapped or emotionally disturbed. A breakdown of the number who are developmentally handicapped is not available.

b Board and lodging with no programming.

c The data shown here are for persons with a primary diagnosis of mental retardation. In addition, the Homes for Special Care Program accommodates 603 individuals with mental retardation as a secondary diagnosis, for a total of 3092.

d Nursing homes accommodate 1807 adults and 170 children with a primary diagnosis of mental retardation. Some homes are exclusively for adults or for children; some mix the two.

SOURCES: Inventory of Social Service Programs for Adults, January, 1982; MR Services Unit, Children's Accommodation Inventory; Children's Advocacy Information System; Facilities for Troubled Children and Youth; Tri-Ministry Project in Homes for Special Care and Nursing Homes.

APPENDIX 2

The Group Home Policies of Ontario Municipalities

TABLE A: AN OVERVIEW

Population size	Number of municipalities surveyed	Have or are considering the Group Homes Policy	Retain a spot-rezoning process	Total population represented
Over 100,000	17	13	4	4,250,793
50,000 to 100,000	15	13	2	1,044,735
25,000 to 50,000	24	15	6[a]	652,243
Under 25,000	76	37	39	715,942
Total	132	78	51[a]	6,663,723[b]

a. The decisions of three municipalities are unknown

b. = 77% of Ontario's population

Source: Secretariat for Social Development, 1982

TABLE B: SPECIFIC MUNICIPALITIES' STATUS

Have Comprehensive Group Home Policies	Have Group Home By-Law with Restrictions		Considering Group Homes Policy	Retain Spot Rezoning
Anderson	Barrie	- Permits all; up to five unrelated people; homes for offenders in commercial zones.	Ajax	Ancaster
Beeton	Brampton	- Permits all except homes for offenders	Alliston	Anson/Hindon/Minden
Cumberland	Brantford	- Permits all via lodging and boarding homes	Cambridge	Aurora
Eganville	Burlington	- Permits all via definition of family	Chatham	Aylmer
Ganonoque	Dundas	- Permits all; may restrict zones or size	Cobourg	Belleville
Georgina	East Gwillimburry	- Permits all in industrial or commercial zones only	East York	Brantford
Gloucester	North York	- Permits all but restricts correctional homes to arterial roads	Essex	Brock
Hamilton	St. Thomas	- Permits as lodging and boarding homes in R_2 and higher density zones	Fort Erie	Caledon
Kingston	Sarnia	- Permits all on arterial or collector roads	Goderich	Delhi
Little Current	Scarborough	- Permits only homes for developmentally handicapped	Guelph	Dryden
London	Sudbury	- Permits via definition of family	Hawskesbury	East Williams
Metropolitan Toronto	Uxbridge	- Permits only homes for children and developmentally handicapped	Ingersol	Etobicoke
Nepean			Innistil	Flamborough
Nickel Centre			Kitchener	Forest
Onaping Falls			Kingston	Glanbrook
Ottawa			Mississauga	Goulbourn
Petawa			Morson	Grimsby

TABLE B: SPECIFIC MUNICIPALITIES' STATUS

Have Comprehensive Group Home Policies	Have Group Home By-Law with Restrictions	Considering Group Homes Policy	Retain Spot Rezoning
Ridgetown	Vanier - Permits all in four out of 7 zones	Newcastle	Halton Hills
Thessalon	York - Permits all except homes for offenders and alcoholics	Newmarket	Kanata
Toronto (City of)		Niagara Falls	Kenora
Tottenham		Niagara-on-the-Lake	King
Whitechurch-Stouffville		North Bay	Lakefield
		Oakville	Lincoln
		Orangeville	Malden
		Orillia	Markham
		Oshawa	Maryborough
		Owen Sound	Matchedash
		Parry Sound	Medonte
		Pelham	Midland
		Pickering	Naticoke
		Port Colbourne	North Dumphries
		Port Hope	Osgoode
		Richmond Hill	Pembroke
		Sault Ste. Marie	Peterborough
		Simcoe	Renfrew
		Stoney Creek	Rideau
		Thorold	Rockcliffe Village

TABLE B: SPECIFIC MUNICIPALITIES' STATUS

Have Comprehensive Group Home Policies	Have Group Home By-Law with Restrictions	Considering Group Homes Policy	Retain Spot Rezoning
		Trenton	St. Catharines
		Waterloo	Scugog
		Welland	Smith
		Whitby	Thunder Bay
		Woodstock	Vaughan
			Wainfleet
			Wellesley
			West Carleton
			West Lincoln
			Wilmot
			Woolwich

APPENDIX 3

Responsibility for Group Home Programs

Name of Program	Ministry	Governing Legislation
Approved Homes	Health	The Mental Hospitals Act (R.S.O. 1970, C. 270, R.R.O. 578)
Homes for Special Care	Health	The Homes for Special Care Act (R.S.O. 1970, C. 205, R. R.) 438)
Community Resource Centres	Correctional Services	The Ministry of Correctional Services Act, 1978 (R.S.O. 1978, C. 37)
Halfway Houses for Alcoholics	Community and Social Services	The Charitable Institutions Act (R.S.O. 1970, C. 62)
Halfway Houses for Ex-Offenders	Community and Social Services	The Charitable Institutions Act (R.S.O. 1970, C. 62)
Halfway Houses for Socially Disadvantaged	Community and Social Services	The Charitable Institutions Act (R.S.O. 1970, C. 62)
Satellite Residences for Seniors	Community and Social Services	The Homes for the Aged and Rest Homes Act (R.S.O. 1970, C. 206, R.R.O. 439)
Accommodation Services for the Mentally Retarded	Community and Social Services	The Homes for Retarded Persons Act (R.S.O. 1970, C. 204, R.R.O. 437, O. REG. 205/77) The Developmental Services Act (R.S.O. 1974, O. REG. 213/74)
Children's Residences	Community and Social Services	The Children's Residential Services Act, 1978, (R.S.O. 1978, C. 70, O. REG. 936/80)

APPENDIX 4

Proposed Clarification of the "50/50 Rule" for Admissions to Group Homes for the Developmentally Handicapped

1. Operators of all new or existing homes that receive funds under The Developmental Services Act or The Homes for Retarded Persons Act (excluding government-operated Facilities) must ensure that at least 50 per cent of all external admissions into permanent beds are of individuals who have been discharged directly from either a Schedule I or a Schedule II Facility. An external admission is defined as an admission to a permanent bed/place from outside the local accommodation service (it does not include internal transfers).

2. The 50 per cent quota may be spread across the full fiscal year (1 April to 31 March) provided that it is realized overall by year end.

3. On agreement of the appropriate Area Office, the 50 per cent quota may be spread across all accommodation units operated by a given agency or a specified group of agencies provided that the overall minimum of 50 per cent is realized for the Ministry Area as a whole.

4. A resident admitted from a Schedule I or II Facility who is readmitted to that Facility within three months may not be counted toward the 50 per cent quota.

5. Residents who have been placed temporarily in an intermediate location (following discharge from a Facility and prior to admission into the community home) may be counted toward the 50 per cent quota only if the admission to the community home was jointly planned and scheduled at the time of discharge from the Facility.

6. Community residences may not include in the 50 per cent quota any person who has not resided in the discharging Facility more than six months.

APPENDIX 5

Alternative Means of Measuring the Level of Service Required by Individuals in Residential Care

Chapter VII of this paper suggests a funding system for the residential models proposed in this paper. In order for the funding system's Level Two (Basic Program Costs) to operate effectively, it is essential that a means be devised of measuring the level of service required by each individual in residential care. Such a measure could be developed in one of four ways:

1. Computation of the hours of service required for an individual by specifying in detail all of the activities in which staff will be involved with that individual and the amount of time required for each activity.*

   The advantages of this approach are:

   a. It clearly attempts to tie staffing hours to the needs of each individual;
   b. The information could be taken from or used in the development of an Individual Program Plan.

   The disadvantages of this approach are:

   a. It is very time consuming and complex to make such an assessment and to relate it to hours required. It would be so onerous a task that it would be difficult to get staff and workers to use it;
   b. It would be very difficult if not impossible to make up a complete list of the activities that may have to occur;
   c. The logistics of such an approach would make it impossible to use as an aid to residential placement;
   d. It would be difficult to separate Level Two and Level Three needs from each other.

2. A second approach could be called the functional approach. It would involve the measurement of the level of skill that a client has in a variety of functional areas, particularly life skills and interpersonal skills, the assignment of a number of hours to persons at each level of adaptive functioning and adding hours across areas and individuals.

   The advantages of this approach are:

   a. It is apparently very simple;
   b. A number of instruments exist for measuring adaptive functioning;
   c. The information could be used in the development of an individual program plan.

---

* A variant of this approach would be to relate the amount of time assigned to an activity not to each individual's requirements but to a standardized estimate (for example, to stipulate that feeding requires a certain number of minutes per day). In fact, however, the amount of staff time required to feed individuals, even if assessed at the same level on a standardized instrument, may vary as a result of other concomitant factors, such as physical impairments, behavior problems, intellectual skills, and so on.

There are, however, a number of disadvantages:

a. The instruments are not likely to be comprehensive - that is, they are not likely to include all of the activities that may be engaged in on behalf of a particular client. If they were, they would become too cumbersome and time consuming;
b. Physical impairments, behavior problems, and medical problems affect the time required for activities. Although an instrument could take this fact into account to some extent, the list would almost certainly not be comprehensive, and the time required for these other activities may be significantly affected by these impairments.

3. A third approach, the one that has been most commonly used, is the labling or impairment-identification approach. It involves specifying the number of hours of care per day (or the ratio of staff to residents) required by people who are severely retarded, profoundly retarded, and so on. Sometimes this approach attempts to take into account other factors, such as behavioral or physical impairments, resulting in a description of classes of people. This somewhat elaborated labeling approach has been used by the Accreditation Council on Mental Retardation and Development Disabilities.

   The primary advantage of this approach is its simplicity. It has, however, a number of disadvanages:

   a. It takes only a small number of factors into account;
   b. It does not attempt to weigh these factors in any way;
   c. The resulting categories are not always mutually exclusive.

4. The fourth involves a mixture of the functional approach combined with a somewhat elaborate version of the impairment-identification or labeling approach. This would entail the use of an instrument (such as the one in Appendix 2) that would permit one to pull together, in a relatively simple manner, standardized assessment information on all persons requiring residential services.

   This instrument would assess disability level in four areas: physical/sensory, life skills, intellectual, and behavioral/emotional. The items comprising the instrument, which would require 10 to 15 minutes to administer by a knowledgeable informant, would be weighted to reflect a professional consensus regarding the level of staff input required at each level of disability. The scores would then be multiplied by a constant (derived both from professional opinion, and an examination of the current empirical reality) to arrive at an estimate of the number of hours of care per day required by each individual in a residence.

   These scores would than be totaled across individual's to arrive at a figure for an entire residence. The figure would be translated into the number of person-years required to provide this level of service, which would remain constant until reassessment the following year.

The advantages of this system are:

a. It takes into account more factors than does a simple labeling or categorical approach (e.g., "severely retarded"), and so on;
b. It permits the influence of behavioral, medical, and intellectual impairments to be taken into account;
c. It is not as time consuming as the specification of individual hours based on IPPs or the functional approach using a detailed adaptive behavior assessment;
d. It does not require a complete list of all possible activities or programs that might be engaged in on behalf of a resident;
e. It is similar in many respects to the Resident Statistical System and could be employed in a standaridzed information system for residential care.

Its disadvantages are:

a. It does not directly measure the hours of service required;*
b. It would have limited utility in developing Individual Program Plans.

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* In fact, none of the approaches except the first can be tied directly to hours of service needed. In order to arrive at such a relationship, it would be necessary to use some combination of expert consensus along with some checking against empirical reality.

APPENDIX 6

An Example of an Instrument for Measuring levels of Disability

Physical/Sensory Capacities

		WEIGHT
Hearing	No significant difficulty	0
	Difficulty only with faint speech	3
	Frequent difficulty with normal speech	10
	Frequent difficulty with loud speech	15
	Can understand only shouted or amplified speech	20
	Usually cannot understand even amplified speech	30
Vision	Within normal limits	0
	Loss suspected but not assessed professionally	5
	Some impairment	15
	Substantive impairment, but not legally blind	25
	Some usable vision, but legally blind	40
	No usable vision	50
Mobility	Within normal limits	0
	Difficulty but uses stairs (balance problems)	5
	Partial ambulation, does not use stairs or uses them only with physical assistance	10
	Wheelchair or equivalent without assistance	15
	Wheelchair or equivalent with assistance	30
	Not Ambulatory	50
Manual Dexterity	Within normal limits	0
	Minimal fine motor coordination, shaking, difficult with smaller objects	10
	Usable gross motor coordination	20
	No use of hands (may use compensations skill)	40
Seizures	No seizures	0
	Infrequent petit mal seizures	5
	Frequent petit mal seizures	15
	Infrequent grand mal/psychomotor seizures	20
	Frequent grand mal/psychomotor seizures	25
	Very frequent grand mal/psychomotor seizures	30
Other Physical/ Medical	Medical/physical probelms of moderate severity	5 each
	Medical/physical problems of severe significance	10 each
	OTHER PHYSICAL/MEDICAL MAXIMUM	40
	POSSIBLE TOTAL	240

Life Skills

Receptive Language	Understands normal converstion (speech, sign language, Blissymbols)	0	WEIGHT
	Understands phrases and simple sentences (speech, sign language, Blissymbols)	5	
	Limited understanding without use of gestures	15	
	Limited understanding when gestures used	20	
	No response to language or gesture	25	
Expressive Language	Normal conversation in speech, sign language, or Blissymbols	0	
	Uses two or three-word phrases in speech, sign language, or Blissymbols	5	
	Uses single words, sign language, or Blissymbols	10	
	Expression only through pointing, gesturing, vocalizing	15	
	No attempt to communicate needs/desires	20	

	Independent	Needs supervision/ training; requires verbal prompts	Requires substantial verbal and/or some physical assistance	Can perform with direct physical assistance	Almost totally dependent
Toileting	0	5	15	30	50
Eating	0	10	20	35	50
Dressing	0	5	10	15	20
Personal hygiene	0	5	10	15	20
Travelling	0	5	15	20	25
Cooking	0	5	8	11	15
Cleaning	0	2	4	7	10
Shopping	0	1	2	3	5
Handling money	0	1	2	3	5
Academic	0	1	2	3	5

WEIGHT

TOTAL 250

Functioning Level

Intellectual functioning	Borderline or higher	Mild	Moderate	Severe	Profound
	0	15	30	60	80

WEIGHT

TOTAL 80

Behavior/ Emotional Problems	FREQUENCY AND SEVERITY											
	0	1	2	3	4	5	6	7	8	9	10	SCALE*
Aggression - others	0	5	10	15	20	25	30	35	40	45	50	WEIGHT
Aggression - self	0	5	10	15	20	25	30	35	40	___45___		
Aggression - property	0	5	10	15	20	25	30	35	___	40	___	
Other anti-social behavior	0	3	6	9	12	15	18	21	24	27	30	
Other behavior disorders (including neurotic behavior)	0	2	4	6	8	10	12	14	16	18	20	
Psychotic behavior	0	5	10	15	20	25	30	35	40	___45___		

TOTAL 230

Overall Functioning Index Total Score: 800

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* See pp. 28-32 for behavioral/emotional scale

GUIDELINES FOR MEASURING LEVEL OF DISABILITY

Physical/Sensory Capacities

HEARING

No significant difficulty (20db)	Experiences no significant difficulty in hearing normal speech, most softly spoken speech, or most environmental sounds relevant to his/her safety (e.g., fire alarms, smoke detectors, automobile horns).
Difficulty only with faint speech (25db)	Experiences some difficulty with quiet speech or soft sounds, such as a kettle boiling, light knock on the door, but can readily hear sounds indicating hazard (e.g., fire alarms, smoke detectors).
Frequent difficulty with normal speech (40db)	Frequently tends to miss or lose parts of normally spoken speech. Has difficulty hearing many environmental sounds, such as running water in a sink, approaching traffic. Can still hear loud sounds, alarms. Requires a hearing aid to receive many/most sounds and speech adequately.
Frequent difficulty with loud speech (55db)	Tends to lose parts of loudly spoken speech. Must be spoken to slowly and quite loudly. Requires frequent repetition of speech to receive a message. Cannot adequately hear many environmental sounds, such as smoke detectors, ringing telephone and door bells, but can still hear shouted speech and loud fire alarms, automobile horns. Requires a hearing aid. May use sign language or Blissymbolics.
Can understnd only shouted or amplified speech (70db)	Cannot receive normally spoken speech and often experiences difficulty with shouted speech unless it is very slow and clear. Frequently tends to rely on visual cues to assist in obtaining a message. Cannot hear most environmental sounds, such as telephone ringing, door bell, alarm clock, smoke detector. In addition, cannot adequately hear warning sounds such as fire alarms, automobile horns. Requires strong hearing aid, tends to distort sounds. May use sign language or Blissymbolics.
Usually cannot understand even amplified speech (91+db)	Can midly hear only very loud, clear sounds at close range (e.g., whistle). Does not hear shouted speech or environmental sounds relevant to personal safety (fire alarms, warning bells, automobile horns). Hearing aid provides only minimal improvement to hearing. May rely totally upon visual cues to receive message(s)/conversation. May use sign language or Blissymbolics.

VISION

Within normal limits	Can discriminate small and large, near and distant objects equally well. Can see all objects relevant to personal safety and well-being (e.g., obstacles in the environment, such as broken glass or wet floors, warning labels on hazardous materials, traffic lights, approaching vehicles). Requires no physical assistance.
Loss suspected but not assessed professionally	Occasionally experiences difficulty in some areas (e.g., cannot see small objects close up or objects at a distance). Has problems sorting/discriminating fine detail or identifying more distant objects (e.g., people). Can see well enough to avoid danger or accidents and hazardous materials (e.g., wire or cord on floor, small furniture, steps, traffic lights). Requires no physical assistance but may require an occasional verbal cue. May require "reading" glasses, glasses for distance.
Some impairment	Has frequent difficulty with discriminating near or distant objects, (e.g., may often confuse forks and spoons, cannot see buttons, pins, or coins very well) or cannot see traffic and public utility signs clearly. Usually can identify hazardous elements and situations, such as vehicular traffic, stairways, landings, but may frequently miss small steps or wet floors, etc. Requires visual aid to see adequately. Requires verbal cues to assist in coping with all environments.
Substantial impairment but not legally blind	Has great difficulty discriminating near, distant (or both) objects and stimuli. Cannot see environmental hazards or potential hazards well enough to avoid accident or injury. Many verbal cues are needed to assist in coping with everyday living as well as tactile cues and/or a specially setup or "routine" environment (e.g., furniture, utensils arranged in a routine order). Requires visual aid(s) and supervision.
Some usable vision but legally blind	Possesses enough vision to be able to see bright objects, light and shade (i.e., very magnified stimuli). Cannot see hazards in environment and has considerable difficutly in finding way around an unfamiliar environment. Requires extensive adaptions to living environment to cope. Also requires tactile and verbal cues consistently. May use cane or other sounding apparatus. Requires constant supervision in a crisis or emergency.

No usable vision	Must be assisted physically, verbally, or tactilely to cope with environment. Requires specialized adaptions to the environment to function independently. Cannot avoid some safety hazards without assistance (e.g., crossing a street, wet floors, hazardous spilled liquids). Requires supervision and assistance in a crisis or emergency (e.g., fire).

MOBILITY

Within normal limits	Can walk, run, etc. sufficiently well over most surfaces (i.e., pavement, stone, grass, dirt) to travel on foot without assistance. Rarely has accidents as a result of loss of balance or unsteadiness. Can move quickly enought in an emergency to get to safety (e.g., exit during a fire).
Difficulty but uses stairs (balance problems)	Unsteady gait, spasticity of limb movement, physical impairment to limbs, or fluid-balance impairment. Can maneuver most situations but requires more time to complete movement. Has occasional accidents - falls over irregular surfaces or when balance is challenged quickly (e.g., when standing on a bus that stops abruptly).
Partial ambulation does not use stairs or only with physical assistance	Mobility restricted to ground-level and even surfaces. Tolerance for stairs, irregular surfaces is poor because of physical/balance impairment or a physical aid cannot be accommodated in these situations (e.g., a walker on stairway). Generally moves slowly and requires physical assistance to exit quickly during an emergency. May also require assistance in bathing.
Wheelchair or equivalent without assistance	Mobility limited to areas that can accommodate physical aid. Requires physical assistance to travel stairways, irregular surfaces, and to open/close some doors. Movement is generally slower than normal; therefore, requires assistance during an emergency. May require assistance in using aid (e.g., getting in and out of a wheelchair). May require physical assistance in bathing, toileting. May have additional aids in environment (e.g., ramps, seating).
Wheelchair or equivalent with assistance	Cannot operate/manipulate physical aid/mobility aid without assistance from others (as in the case of severe quadraphalegia). Requires physical assistance to perform most bathing and toileting tasks. May not be able to sit unsupported. Must be physically assisted to exit quickly during an emergency. May have specially designed aids in environment (e.g., special seating, ramps).

Not ambulatory	Cannot operate a wheelchair or equivalent even with assistance. Physical impairment may be so severe as to prevent seating or placement in an aid. May also have extreme difficulty rolling or "crawling". Requires physical assistance to perform most or all bathing and toileting tasks. Requires physical assistance to arrive at safety during an emergency. Requires support to remain in a sitting position. Requires special devices and/or attention to prevent sores, poor circulation, etc.

MANUAL DEXTERITY

Within normal limits	Experiences no difficulty performing both gross motor activities (e.g., reaching and grasping large objects such as plates, utensils) and fine motor tasks (e.g., putting toothpaste on toothbrush). Can execute activities requiring coordinated hand movements, such as writing, drawing, lacing shoes. Does not require assistance to perform activities of daily living, such as manipulating utensils, buttoning, zippering, lacing.
Minimal fine motor coordination; shaking, difficulty with smaller objects	Can adequately perform most gross motor activities (e.g., can dress self) but requires assistance to complete fine motor tasks, such as buttoning, zippering, lacing. Experiences some difficulty with reaching, grasping, and/or maintaining a grip on objects. Often spills liquids in small containers (e.g., teacups) or drops food from utensils because of unsteadiness/spasticity. May require physical aids (e.g., plate guards, suction cups) to assist in everyday tasks.
Useable gross motor coordination	Manual skills limited to gross motor activities such s reaching and grasping/manipulating large objects (e.g., towels, shoes). Cannot perform fine motor activities without physical assistance or numerous adaptions to the environment (e.g., hand grips for utensils, hand-over-hand). Has difficulty holding objects for any length of time (because of muscle weakness, spasticity). Requires considerable physical assistance to complete most activities of daily living involving fine motor steps (e.g., brushing teeth, clipping nails, buttoning, zippering, lacing). May have fair ability to control prosthesis.
No use of hands, may use compensating skill	Not able to perform tasks that cannot be adapted by special aids. May have workable prosthesis but requires assistance to control movements. Generally cannot complete fine-detail work requiring "finger" manipulation. Requires assistance to complete life skills such as buttoning, zippering, lacing.

SEIZURES

No seizures	No known seizure activity. May have been treated for epilepsy in the past but has had no seizure activity for previous two years.

Infrequent petit mal seizures	Occasional petit mals that create no significant difficulty. Medication controlled. No history of grand mal seizures.
Frequent petit mal seizures	May experience several petit mals during the day that interrupt appropriate activity level. Requires attention to insure participation in and continuity with a task. May have occasional grand mal. Medication controlled for grand mals.
Infrequent grand mal/psychomotor seizures	May experience frequent petit mals but infrequent grand mals/psychomotors (e.g., 1 to 3 per month). Generally, seizures are controlled by medication. Requires supervision in certain activities (e.g., swimming).
Frequent grand mal/ psychomotor seizures	Requires fair degree of supervision to ensure protection from injury during certain activities (e.g., bathing, using stairways, handling sharp objects). May require bed checks in evening if epilepsy occurs after bedtime. Is not stable on medication. Grand mal/psychomotor episodes may be cyclical. (4 to 10 seizures per month)
Very frequent grand mal/psychomotor seizures	Requires heavy supervision during activities where a fall would/might create considerable injury (e.g., bathing, using stairs, riding escalators). Requires bed checks if nocturnal epilepsy is present. May require head protection. Attending behavior (i.e., drowsiness, stupor) may inhibit participation in activities. Not controlled on medication. (11 or more seizures per month).

OTHER PHYSICAL/ MEDICAL

Medical/physical problems of moderate severity	Include specific allergies, asthma, chronic inflamations that prevent or inhibit the ingestion of or contact with, several foods/materials. Reactions generally tend to be quite severe. Also include physical impairments, such as bowel, bladder problems, that necessitate specialized medical supervision or physical problems that limit participation in many activities (e.g., macrocephaly).
Medical/physical problems of severe significane	Include rare syndromes that are chronic-terminal and that are characterized by progressive deterioration in functioning (e.g., San Fillipo syndrome). Also include physical impairments that are life-threatening (e.g., heart irregularities).

Life Skills

RECEPTIVE LANGUAGE

Understands normal conversation	Can understand normal, everyday speech and language. Can understand directions and interpret most nonverbal signals and cues (e.g., facial expressions, shrugging shoulders). Can understand fairly complex sentences.
Understands phrases and simple sentences	Can understand brief, simple conversations that emphasize concrete nouns and action-oriented verbs and involve only minimal abstract concepts (e.g., "Who's washing dishes tonight?"). If sign language or Blissymbolics is used, understanding is limited to simple, distinct noun signs and symbols.
Limited understanding without use of gestures	Understands only basic, rudimentary speech. Requires physical gesturing or props to assist in comprehending directions, instructions. Understands only very elementary signs and Blissymbols.
Limited understanding when gestures used	In general, shows little awareness of spoken language, gestures, and/or visual props. Communications are limited to single words and generally must be repeated for comprehension to occur. Cannot understand or has not been introduced to signing or Blissymbols.
No response to language or gesture	Indicates no awareness of speech, gestures, signing, Blissymbols. Must be directed to most things hand-over-hand or must be led into activity to comprehend (e.g., must be brought to dinner table for "supper's ready", must be placed in bathtub for "time for a bath").

EXPRESSIVE LANGUAGE

Normal conversation	Can express him/herself sufficiently well to exchange ideas, thoughts and to communicate both physical and emotional needs. Can discuss problems and related personal concerns. Speech content is generally clear, and articulation is good. Will initiate conversation and maintain dialogue when appropriate.
Uses 2 to 3-word phrases in speech, sign language, or Blissymbolics	Uses simple phrases but not long or complex sentences. Can make needs known but has difficulty elaborating. May require prompt to initiate conversation. Communications may be difficult to follow because of choppy nature of "speech". May experience difficulties because of aphasia. Uses basic signs or Blissymbols.

Uses single words, signs, or Blissymbols	Expresses him/herself in single nouns, adjectives or action verbs (e.g., "supper?...Hungry!"). Has difficutly expressing less immediate needs (e.g., "home" -indicating that he/she would like to see parents). Usually requires a great deal of common physical gesturing and/or visual props to make self understood. Signing or Blissymbols are quite limited. Tends to rely on "routine" or long-standing pantomimes/behavior to make usual needs known.
Expression through pointing, gesturing, vocalizing only	Cannot usually express him/herself in conventional speech, signing, or Blissymbols. Relies heavily upon environmental props and gesturing to indicate needs (e.g., may lead another person to medicine chest to indicate a pain or discomfort, rub stomach to indicate fullness or satisfaction). May suffer impairment of the mouth muscle or vocal cords that prevents speech.
No attempt to communicate needs/ desires	Shows almost no awareness of self-expression through verbalization, vocalization, gesturing, signing, or Blissymbols. Does not communicate basic needs, emotions, desires. Vocalization may occur in the case of severe pain or in the presence of distress. Occasionally may make sounds/gestures more for their own benefit or self-stimulation than as a genuine attempt to communicate with others.

TOILETING

Independent	Requires no reminders to use toilet when needed. Will toilet self prior to long trips, outings, etc. Requires no assistance and can adjust all clothing neatly.
Needs supervision/ training - requires verbal prompts	Needs reminder to toilet prior to outings. Cannot independently toilet in unfamiliar surroundings (e.g., public washrooms). Must be reminded occasionally to wash hands, tidy clothing.
Requires substantial verbal and/or some physical assistance	Must usually be reminded to toilet throughout the day. Occasionally requires physical guidance to actually go to the bathroom. Requires verbal instructions to complete the tasks including hygiene afterward. May be in maintenance phase of toilet-training program. Has occasional accidents.
Can perform with direct physical assistance	Requires considerable physical guidance, or assistance to toilet (e.g., placing on toilet, hand-over-hand instruction). May be physically handicapped or in initial stages of toilet-training. May be habit trained only. Has frequent accidents if left unattended/unsupervised, particularly at night. Can indicate a need to toilet.

Almost totally dependent	Cannot perform any portion of toileting without extensive physical assistance. Indicates little or no awareness of need to toilet. In incontinent.

EATING

Independent	Able to manipulate all necessary utensils - forks, spoons, knives. Does not require any verbal prompts or reminders to maintain social manners during mealtimes. Eats in a reasonable length of time and can engage in conversation during meals when appropriate. Does not experience any particular difficulty with a variety of food textures (e.g., chewy, crunchy, liquid).
Need supervision/ training - requires verbal prompts	Requires occasional reminders to use knife, napkin or to slow down/speed-up eating. May need reminders to cleanup after self and to maintain appropriate manners throughout mealtime.
Requires substantial verbal and/or more physical assistnce	Needs constant reminders to maintain correct use of utensils, to avoid gulping or choking on food or to eat more quickly. Needs direction in order to begin with appropriate course (i.e., main course before desert). May have difficulty in scooping and/or cutting certain foods and, therefore, may require special adaptions, such as buildingup utensils, plate guards, suction cups.
Can perform with direct physical assistance	Requires hand-over-hand assistance to complete a meal. Needs foods cut or requires considerable physical manipulation in order to cut or scoop foods. Usually requires plate guards, suction cups, etc. Requires verbal cues to take up appropriate foods. May need assistance in seating and in obtaining food on plate. May be able to eat finger foods and some pureed foods (if he/she has not developed adequate chewing and swallowing skills).
Almost totally lacking	Requires constant physical assistance. May not be able to lift spoon/fork or may have minimally developed chewing/swallowing skills. May have medical or nursing problems that inhibit eating behavior. May require a highly specialized diet because of health or physical complications.

DRESSING

Independent	Can perform all activities related to dressing self including choosing appropriate clothing for climate, occasion, and age.
Needs supervision/ training - requires verbal prompts	Needs direction in choosing wardrobe, in attending to detail (e.g., color coordination, tucking in shirt or blouse, tying tie). May need reminders to change clothing and to maintain care of shoes, coats, etc.

Requires substantial verbal and/or some physical assistance	Must be instructed to dress appropriately to climate (e.g., heavier clothing in cooler weather). Needs reminders to change clothing, to fasten zippers and buttons, to tie laces. May need demonstrations and/or some hand-over-hand assistance to complete certain tasks such as shoelace tying. Can look after clothing such as boots, shoes.
Can perform with direct physical assistance	Requires hand-over-hand assistance, gestures, and some passive dressing in order to complete task of dressing self. Usually requires instructions to begin dressing, and occasionally may need prompts to continue with task. Must have wardrobe completely laid out for him/her. Requires instruction to dress appropriately even in extreme weather conditions.
Almost totally dependent	May be bedridden and unable to dress independently although may be aware of dress and indicate personal preferences. Usually must be physically dressed by staff. Indicates no awareness of clothing needs of is unconcerned with needs. May be able to complete preliminary steps of dressing (e.g., last few steps in backward chaining of putting on pants) but requires prompting. Cannot be depended upon to dress for protection from weather.

PERSONAL HYGIENE

Independent	Performs necessary hygiene tasks such as showering/bathing, toothbrushing, without reminders. Demonstrates and ability to maintain hygiene routines relevant to health and sanitation. Usually appears interested in self-appearance.
Needs supervision/ training - requires verbal prompts	Needs reminders to attend to hygiene matters (e.g., toothbrushing). Can usually complete most tasks independently once reminded of the need; however, may require some verbal prompts to groom self thoroughly, (i.e., may forget to comb hair). May still need training in certain areas, such as correct toothbrushing.
Requires substantial verbal and/or some physical assistance	Needs constant reminders and instructions to attend to hygiene needs. Usually will not complete a task without supervision. May hurry or plod through necessary grooming. May require hand-over-hand for more difficult activities, such as combing back of hair, clipping nails. May not be aware of self-appearance.
Can perform with direct physical assistance	Cannot complete hygiene without substantial physical help (e.g., bath - drawing water, controlling temperature, applying soap - toothbrushing). If in a wheelchair, may require assistance only for major tasks such as bathing.

Almost totally dependent	Indicates no awareness of need for hygiene or may be unable to complete any steps because of a physical handicap. Must be passively bathed or showered and groomed. May be at initial training stages but cannot complete the necessary steps without staff intervention.

TRAVEL

Independent	Can travel to and from most common everyday places unsupervised. As appropriate, can use public transportation, taxi, or foot to reach a destination. Can be relied upon to negotiate most travel arrangements, such as meeting a bus on time, learning bus/subway schedule, or calling a taxi independently. Where private van is the only form of vehicular traffic available, might be expected to exhibit awareness of van schedules.
Needs supervision/ training - requires verbal prompts	Needs guidance to observe bus schedules, to call a taxi, and to orient to new travel routes. May be able to travel short distances unassisted, but usually requires verbal instructions to ensure safe passage (i.e., road safety awareness). May live in an area where public transporatation is inaccessible and therefore rely on walking to a local store, etc.
Requires substantial verbal and/or some physical assistance	Can manage to orient self to surrounding neighborhood but is unable to travel to local sites (e.g., stores) without verbal guidance along route. Usually requires supervision for most trips and does not negotiate public transportation or taxi without extensive assistance.
Can perform with direct physical assistance	Must be supervised for all trips outside immediate vicinity of home. Has little road-safety awareness and therefore does not use public transportation if available. Must be assisted to use taxis (i.e., staff must place call, give driver destination, and arrange payment). Unable to travel by road to local stores, etc. without being accompanied.
Almost totally dependent	Does not usually walk unsupervised. Requires one-to-one assistance during outings. Becomes quickly disoriented in new surroundings and must be led by others. Has minimal/no road-safety awareness - may run/walk out into middle of road; therefore, must be supervised.

COOKING

Independent	Can prepare and plan basic meals involving simple, straightforward steps. Can follow short recipes and use most kitchen appliances with little difficulty. Is careful of cutting implements and knows importance of proper food storage practices.

Needs supervision/ training - requires verbal prompts	Can prepare foods requiring simple defrosting and heating/reheating. Usually can "cook" basic canned foods, such as soups, stews, etc. Requires further training to operate most kitchen appliances and does not understand all components of food storage, cleaning, and preparation (e.g., refrigerating vegetables and dairy products, washing fruits/vegetables).
Requires substantial verbal and/or some physical assistance	Can prepare snacks and sandwiches but requires supervision and step-by-step verbal guidance. For more difficult procedures (e.g., opening can with can opener) must be assisted physically. Usually does not operate any kitchen appliances and/or sharp objects unsupervised/unassisted. Requires guidance to distinguish between foods that must be cooked and those that may be eaten raw.
Can perform with direct physical assistance	Is able to perform preliminary activities of "cooking" with physical help (e.g., may be able to pour contents of a can into a pot, obtain a variety of ingredients from shelves, fridge, prepare cold foods such as cereal). Does not exhibit enough awareness of safety precautions to be able to use kitchen appliances even with assistance.
Almost totally lacking	Concept of cooking is severely limited. May be able to recognize that foods generally require cooking and/or that foods are kept in the fridge but has no knowledge of the basics involved and is not able to prepare even simple snacks.

CLEANING

Independent	Can manage most household chores, such as washing dishes, sweeping, dusting. Can clean and care for own clothing. Usually keeps personal area reasonably clean and organized without any reminders or assistance. Has general knowledge of the use of cleaning fluids, tools, etc.
Needs supervision/ training - requires verbal prompts	May perform most cleaning tasks well if given initial instructions on most occasions. Keeps personal area reasonably clean but requires prompts to do so consistently. Does not have good knowledge of the use of various cleaning fluids. Can assist in washing own clothing.
Requires substantial verbal and/or some physical assistance	Requires step-by-step instruction on most cleaning tasks that are not simple/straight-forward (e.g., washing clothing). In such tasks may need to be assisted physically to complete task. Usually will follow through on a chore if guided in how to do it. Must be reminded to keep up maintenance of personal area.

Can perform with direct physical assistance	Usually understands concepts of cleaning and washing but has little awareness of how to perform these activities. Requires considerable demonstration and hand-over-hand assistance to carry out most house-hold chores. Is able to make own bed and do some basic housecleaning with physical guidance.
Almost totally lacking	Does not initiate any cleaning activities and must be instructed in very basic tasks, such as placing clothing on holder as opposed to dropping on floor, picking up after self. Does not generally participate in most housecleaning chores except in a basic way (e.g., may, with directions, carry dinner plate to sink or counter following meal).

SHOPPING

Independent	Makes small purchases (e.g., socks, gloves) unassisted. Usually participates in any shopping trips and can discriminate between higher/lower priced goods. Is able to judge the quality of an item and can decline a purchase depending on the quality for price. Plans shopping excursions in advance so as to have sufficient funds.
Needs supervision/ training - requires verbal prompts	Often makes small purchases independently, but requires assistance in choosing items and in paying for goods. Has general knowledge of price values but requires explanations/instructions to choose wisely. Usually is accompanied by others when shopping.
Requires substantial verbal and/or some physical assistance	Usually shops for small items when assisted by others. Cannot manage payments unassisted. Can decide personal items, such as cards, some toiletries. Requires supervision in order to shop for appropriate items. Cannot make purchases independently at any time.
Can perform with direct physical assistance	Requires supervision at all times during a shopping trip. Is not aware of concept of purchasing. Tends to choose items without regard to value, appropriateness, or necessity. With close direction and guidance can make a selection and assist in buying it (e.g., can carry item to check-out).
Almost totally lacking	Does not perform any shopping activities, even with constant assistance. Does not exhibit an awareness of what is involved in making selections, paying for them, etc. Does not express much interest in choosing necessary items which are a necessity, (e.g., clothing). May orient more readily to food shopping but may tend to pick up goods and eat them unless supervised.

HANDLING MONEY

Independent	Is able to manage most common, everyday denominations (coins and one-, two-, five-, and ten-dollar bills) and can make change when necessary. Does not require assistance in banking money. Usually remains within a reasonable weekly budget and does not run short of money in midweek or between pay cheques.
Requires supervision/ training - requires verbal prompts	Has basic understanding of various denominations but may require verbal assistance in handling larger bills, such as tens and twenties. May be able to make change but has some difficulty when counting out uneven amounts. Does most of own banking, but needs help in preparing deposit slips, withdrawal slips. Has occasional difficulty budgeting unless given reminders.
Requires substantial verbal and/or some physical assistance	Can manage small amounts of money but usually cannot make change accurately. Handles coins such as pennies, nickles, and dimes independently but does not understand well their relationship to larger denominations such as dollar bills. Does not perform banking activities unless accompanied by and assisted by others. Requires others to manage his/her weekly funds.
Can perform with direct physical assistance	Does not have a good concept of "money". Has minimal knowledge of relative values of coins, bills. Can exchange money for goods if instructed on exactly what amounts to give. Does not perform banking activities except to "authorize" deposits with signature. Does not manage allowance, budget - typically, others do this for him/her.
Almost totally lacking	Is not aware of purpose/function of money. Does not exhibit awareness of values of different coins, bills. Personal funds are handled for him/her. Does not bank.

ACADEMIC

Independent	May be able to read/write, at basic levels but sufficiently well to be able to orient to a new environment, to participate in school courses, to hold a job involving some reading or writing, etc. Has good concept of time and is able to tell time by watch. Can count fairly well and has some understanding of primary calculations such as addition and subtraction.
Needs supervision/ training - requires verbal prompts	Can read some common, everyday words (e.g., "stop", "exit", "washroom") and may be able to sign name. Can tell time fairly well but requires guidance to follow watch accurately. Understands counting and is able to count by ones, fives, etc.

Requires substantial verbal and/or some physical assistance	Requires help to read even everyday words/signs and may need some hand-over-hand help when signing name. Time concept is limited to major distinctions, such as morning, afternoon, evening, and mealtimes. Can orient to times when routine events occur. Counts only by ones and with step-by-step verbal guidance or by rote.
Can perform with direct physical assistance	Does not read well except for a few everyday words such as "exit", "stop", but even then requires assistance. May be able to sign his/her name with hand-over-hand help or to produce a mark/symbol for name. Does not understand time except in a gross manner (i.e., morning, night). Does not count except to repeat numbers.
Almost totally dependent	Does not exhibit any concept of reading, writing. May scrawl or scribble when given paper and pencil. May orient to routine/times, such as mealtimes, but is unable to relate to time of day (i.e., morning, afternoon, evening). Does not count even when verbally prompted. Has minimal concept of quantity, space, etc.

Behavioral/Emotional Problems

AGGRESSION - OTHERS. Includes slapping, scratching, hitting, punching, kicking, gouging, wrestling, choking, pinching threatening with a deadly weapon (such as blunt instrument, knife or gun), stabbing, shooting, hitting with a blunt instrument, setting fire that results in injury, rape or attempted rape, impaired or drunken driving, armed robbery or attempted armed robbery, etc.

AGGRESSION - SELF. Includes slapping, scratching, hitting, punching, kicking, goughing, stabbing, slashing, shooting, ingesting poison or othe toxic substance, drug overdose, suicide attempt, and other self-injurious behavior.

AGGRESSION - PROPERTY (including animals). Includes hitting, kicking, attacking with sharp or blunt instrument, gun, or other mechanically or personally propelled instrument or device, fire-setting (arson), robbery, theft, breaking and entering, and other behavior designed to destroy, damage, or appropriate property.

OTHER ANTISOCIAL BEHAVIOR. Includes inappropriate behavior such as nuisance behavior, public exhibitionism, hoarding, running away, temper tantrums, hyperactivity, swearing, arguing, shouting, attention seeking, mimicry, lying, cheating, masturbating, exposing oneself, smearing or eating feces, suicide threats with no overt action, inappropriate sexual behavior (verbal and minor touching), persistent moving traffic violations, occasion drunkenness.

OTHER BEHAVIOR DISORDERS. (Including neurotic Behavior). Fetishism, withdrawn behavior, depressive behavior, anxious behavior, obsessive compulsive behaviors, stereotyped movements and mannerisms, hypo-activity.

PSYCHOTIC BEHAVIOR. Includes hallucinations, delusions, thought disorders, psychotic depressions, flight of ideas, etc.

FREQUENCY

Rarely	Less than once per month
Occasionally	1-4 times per month (up to and including once per week)
Regularly	2-7 times per week (up to and including once per day)
Frequently	2-16 times per day (up to and including once per waking hour)
Very frequently	More than once per waking hour (17 times per day or more)

SEVERITY

Determination should take into account the extent of:

1. Physical injury to persons including oneself. Relates primarily to aggression against self or others.

2. Impairment of capacity to function in daily activities. Relates primarily to psychotic behavior, less serious antisocial behavior, and other behavior disorders (including neurotic behavior but may also relate to the various types of aggression.

3. Disruption of ongoing behavior and plans of other persons. May relate to any or all of the types of behavior.

4. Property damage or loss. Relates almost exclusively to aggression against property.

5. Potential legal consequences. Relates primarily to aggression against others, aggression against property, and less serious antisocial behavior.

6. Psychic pain to the individual or to others. Relates primarily to aggression against others, other behavior disorders (including neurotic behavior), and psychotic behavior but may also relate to other categories.

In the case of behavior in which more than one dimension is involved, the behavior should be rated at the highest level of severity which obtains.

MINIMAL

Physical Injury. All physical injuries should be rated as mild, moderate, severe or very severe. None should be rated as minimal. Nonserious threats, however, may be classified as minimal.

Impairment. Noticeable, but minimal impairment of previously existing capacity to carry on self-care, day program, or educational or social activities or of the capacity to acquire the skills necessary for such activities.

Disruption. Behavior that disrupts the ongoing program activities and plans of staff, other residents, or citizens for less than one minute per occasion - shouting, screaming, swearing, temper tantrums, other less serious antisocial behavior.

Property. Destruction or theft of property worth less than $1.00.

Legality. Behavior that would incur only mild social censure, mildly annoying habits, etc.

Psychic Pain. Noticeable but minimal psychic pain (e.g., anxiety, fear, depression, sadness).

MILD

Physical Injury. Infliction of minor pain from light blow, kick, pinch or slap, minor scratch or abrasion not requiring bandage, no blood drawn.

Impairment. Mild impairment of previously existing capacity to carry on self-care, day program, or educational or social activities or of the capacity to acquire the skills necessary for such activities.

Disuption. Behavior which disrupts the ongoing program activities and plans of staff, other residents, or citizens for 1-4 minutes per occasion - shouting, screaming, temper tantrums, other less serious antisocial behavior, etc.

Property. Destruction or theft of property worth between $1.00 and $9.99.

Legality. Behavior which would incur moderate to severe social censure but would not usually involve contact with the legal system.

Psychic pain. Mild but obvious psychic pain, e.g., anxiety, fear, depression, sadness, etc.

MODERATE

Physical Injury. More substantial pain from blow, kick, or slap, more severe scratches or abrasions requiring minor treatment, small amount of blood drawn, threat with blunt or sharp instrument.

Impairment. Moderate impairment of previously existing capacity to carry on self-care, day program, educational or social activities or the capacity to acquire the skills necessary to such activities. Needs substantially greater assistance than previously to engage in these activities.

Disruption. Behavior that disrupts the ongoing program activities and plans of staff, other residents, or citizens for five to nine minutes per occasion - shouting, screaming, temper tantrums, other less serious antisocial behavior, etc.

Property. Destruction or theft of property worth $10.00 to $99.99.

Legality. Behavior that could bring the perpetrator a fine, probation, or other punishment that does not involve incarceration.

Psychic pain. Moderate psychic pain (e.g., anxiety, fear, depression, sadness). It would usually entail seeking professional mental health assistance.

SEVERE

Physical Injury. Serious, but not life threatening. Substantial pain from blow, slap, kick, or scratch. Some loss of blood, brief unconsciousness, mild concussion, minor wounds from stabbing with knife or striking with blunt instrument, threat with gun.

Impairment. Severe impairment of previously existing capacity to carry on self-care, day program or educational or social activities or of the capacity to acquire the skills necessary for such activities. Individual is unable to continue with these activities at all or can do so only minimally or with constant attention or supervision.

Disruption. Behavior that disrupts the ongoing program acitvities and plans of staff, other residents, or citizens for 10 to 29 minutes per occasion - shouting, screaming, temper tantrums, running away that may involve a short chase, or other less serious antisocial behavior.

Property. Destruction or theft of property worth $100.00 to $999.99.

Legality. Behavior that could lead to a jail term of less than two years (e.g., drunk or impaired driving, assault and/or battery, minor thefts, threatening with gun).

Psychic Pain. Severe psychic pain requiring professional assistance. Perhaps also delusions, hallucinations, thought disorders, or other serious psychotic behavior.

VERY SEVERE

Physical Injury. Life threatening. Loss or fracture of limb or bone, loss of or severe damage to sensory or other organs or tissues, stabbing with knife, shooting with gun, or serious injury with blunt object.

Impairment. Very severe impairment of previously existing capacity to carry on self-care, day program, or educational or social activities or of the capacity to acquire the skills necessary for such activities. Virtually unable to participate in any of these activities, requiring total assistance.

Disruption. Behavior that disrupts the ongoing program activities and plans of staff, other residents, or citizens for 30 minutes or more per occasion - shouting, temper tantrums, running away, other less serious antisocial behavior.

Property. Destruction or theft of property worth $1,000 or more.

Legality. Behavior that could lead to a jail term of two years or more (e.g., murder, rape, armed robbery, serious assault, major thefts, etc.)

Psychic Pain. Very severe and incapacitating psychic pain requiring professional assistance. Perhaps also delusions, hallucinations, thought disorders, or other serious psychotic behavior.

Frequency	Severity	Scale Score
Rarely	minimal	1
	mild	2
	moderate	3
	severe	6
	very severe	7
Occasionally	minimal	2
	mild	3
	moderate	4
	severe	6
	very severe	7
Regularly	minimal	2
	mild	3
	moderate	6
	severe	7
	very severe	8
Frequently	minimal	3
	mild	5
	moderate	7
	severe	8
	very severe	9
Very Frequently	minimal	3
	mild	5
	moderate	7
	severe	9
	very severe	10

APPENDIX 7

Examples of Estimated Costs for Various Models of Residential Care by Level of Disability

(See TABLE I beginning on page 35.)

Column 1: The types of residence refer to the general models outlined in the introductory section.

Column 2: Level of disability refers to a set of levels also referred to in the introductory section, and based on scores derived from an instrument measuring disability level such as the one in Appendix II.

Column 3: The room and board rates and personal expenses are based on the following: Adults - GAINS-D monthly rate of (\$364 X 12)/365 = \$11.97 per day.

Children - Based on the 1980 rate review formula for parent operated group homes. (\$13.05).

Column 4: This is based on a formula of 1.7 minutes of care per day for each point scored on the instrument in Appendix III. This figure is simply the figure that, multiplied by the scores obtained from the children's residence study, yields a total number of hours per person per day which is equivalent to that which the system currently provides. On the basis of this formula, about 40 per cent of residences would get increased staff, a similar percentage would lose staff, and the remainder would retain the same staffing levels. This figure is being checked for its applicability to adult residences.

Column 5: The rates prepared are approximate figures, involving \$4 per hour for untrained persons (\$5 per hour if some special course relating to residential care and the mentally retarded has been completed), and \$6-8 per hour for persons with an MRC diploma or equivalent training. Higher rates may be paid for senior staff or professional persons, and this possibility is reflected in Column 7, other residential costs, particularly for 24 hour staffed residences.

Column 6: This is simply Column 4 times Column 5.

Column 7: This category includes budget categories such as resident personal expenses, communication, advertising, equipment rentals, professional services, other purchased services, etc., transportation costs of staff and residents, staff training, supplementary salaries for more highly paid staff, and perhaps geographical rent differentials or age room and board differentials.

Column 8: Most of this is self-explanatory.

Column 9: This is simply the sum of Columns 3, 6 and 7.

Columns 10 & 11	These would include other special needs funds plus support services available in the community. Models 6 to 8, alternative and specialized family care and live-in staff would use these community support services most extensively, but other types of residences could also call upon them. Such services would be tied to the needs of an individual resident(s), base on an individual program plan. These services may provide up to one or more coverage for some persons for short periods of time. The details of these services will be covered in the Support Services policy paper.

TABLE I

EXAMPLES OF POSSIBLE COSTS USING THREE LEVEL FUNDING FORMULA AND TYPE OF RESIDENTIAL SETTING

(For total possible program costs including day programs see Table I in Chapter VI. These are not to be regarded as actual costs of programs.)

A = Adults
C = Children

		LEVEL I	LEVEL II						LEVEL III	
Type of Residence	Level of Disability	Board, Room and Personal Expenses	Paid Program Hours of Service	Rate Per Hour	Level II(b) residential Staffing Costs	Level II(b) Other Residential Costs	Comments	Basic Residential Costs 3+6+7	Level III(a) Support Services	Level III(b) Special Needs
1	2	3	4	5	6	7	8	9	10	11
Own Family	Somewhat independent (50-124)	A $11.97-$13.05 C Zero	Zero	-	Zero	A $2.00 C $0-7.40[1]	Parents expected to provide room and board for children up to 5 hours of care per day, may receive payment for up to 4 hours of care	A $13.97-$15.05 C $0-7.40	Variable according to individual need	As required
	Somewhat dependent (125-199)	A $11.97-$13.05 C Zero	Zero	-	Zero	A $2.00 C $0-7.40[1]		A $13.97-$15.05 C $-0.7.40	"	
	Quite dependent (200-274)	A $11.97-$13.05 C Zero	Zero	-	Zero	A $2.00 C $0-7.40[1]		A $13.97-$15.05 C $0-7.40	"	
	Very dependent (475-349)	A $11.97-$13.05 C Zero	Zero	-	Zero	A $2.00 C $0-7.40[1]		A $13.97-$15.05 C $0-7.40	"	

[1] Handicapped Children's Allowance

TABLE I

EXAMPLES OF POSSIBLE COSTS USING THREE LEVEL FUNDING FORMULA AND TYPE OF RESIDENTIAL SETTING

(For total possible program costs including day programs see Table I in Chapter VI. These are not to be regarded as actual costs of programs.)

A = Adults
C = Children

		LEVEL I	LEVEL II						LEVEL III	
Type of Residence 1	Level of Disability 2	Board, Room and Personal Expenses 3	Paid Program Hours of Service 4	Rate Per Hour 5	Level II(b) residential Staffing Costs 6	Level II(b) Other Residential Costs 7	Comments 8	Basic Residential Costs 3+6+7 9	Level III(a) Support Services 10	Level III(b) Special Needs 11
Semi-in-dependent	Somewhat in-dependent (50-124)	$11.97-13.05	3.4 (N.A. for children)	$5.00-$8.00	$ 2.50-28.00	A $2-5.00	One to four residents may be involved	$16.47-$46.05	Variable according to individual need	Average Cost A $1.00
	Somewhat dependent (125-199)	$11.97-13.05	3.5-5.4 (N.A. for children)	$5.00-$8.00	$28-44.00	A $2-5.00		$41.97-$62.05	"	Average cost A $2.00
Alternative Family Care	Somewhat in-dependent (50-124)	$11.97-13.05 ($10.00 board and room)	0-3..4	N/A	$ 0-10.00		Generally for one or two clients. Three in special circumstances.	A $10.00-$20.00 C $10.00-$20.00	Variable according to individual need	As required

TABLE I

EXAMPLES OF POSSIBLE COSTS USING THREE LEVEL FUNDING FORMULA AND TYPE OF RESIDENTIAL SETTING

(For total possible program costs including day programs see Table I in Chapter VI. These are not to be regarded as actual costs of programs.)

A = Adults
C = Children

		LEVEL I	LEVEL II						LEVEL III	
Type of Residence	Level of Disability	Board, Room and Personal Expenses	Paid Program Hours of Service	Rate Per Hour	Level II(b) residential Staffing Costs	Level II(b) Other Residential Costs	Comments	Basic Residential Costs 3+6+7	Level III(a) Support Services	Level III(b) Special Needs
1	2	3	4	5	6	7	8	9	10	11
Special-ized Family Care	Quite depen-ent (200-274)	$11.97-13.05	5.5-7.9	$6.00-$7.00	$33-56.00	A $2-5.00 C $0-5.00	Maximum number of hrs per individual family member (husband or wife) = 8 hrs per day. (Two persons neither of whom has alternative employment max. is 16 hrs per day in total). One to 3 residents may be involved	A $46.97-$74.05 C $44.97-$74.05	Variable according to individual need	As required
	Very dependent (275-349)	$11.97-13.05	8.0-9.9	$6.00-$7.00	$48.00-$70.00	A $2-5.00 C $0-5.00		A $61.97-$88.05 C $59.97-$88.05	"	"
	Extremely dependent	$11.97-13.05	10.00	$6.00-$7.00	$60-70.00	A $2-5.00 C $0-5.00		A $73.97-$88.05 C $71.97-$88.05	"	"
Live-in Staff	Quite depen-ent (200-274) (or somewhat dependent)	$11.97-13.05	5.5-7.9	$7.00-$8.00	$26.25-$40.00 (3-4 residents - 1 staff at all times	$2-10.00	On the assumption staff are on duty 3 days/wk (24 hrs) paid for 15 hrs./day, 2.7 staff min. for 24 hr. 7-day coverage. If one staff on duty each day - paid hrs. per person 3.75, 5 or 7.5.	A $40.22-$63.08 C $40.22-$63.08	Variable according to individual need need	Average Cost A $1.00 C $5.50
	Very dependent (275-349)	$11.97-13.05	8.0-9.9	$7.00-$8.00	$35-60.00 (2-3 residents)	$2-10.00		A $48.97-$83.08 C $48.97-$83.08	"	"

TABLE I

EXAMPLES OF POSSIBLE COSTS USING THREE LEVEL FUNDING FORMULA AND TYPE OF RESIDENTIAL SETTING

(For total possible program costs including day programs see Table I in Chapter VI. These are not to be regarded as actual costs of programs.)

A = Adults
C = Children

		LEVEL I	LEVEL II						LEVEL III	
Type of Residence 1	Level of Disability 2	Board, Room and Personal Expenses 3	Paid Program Hours of Service 4	Rate Per Hour 5	Level II(b) Residential Staffing Costs 6	Level II(b) Other Residential Costs 7	Comments 8	Basic Residential Costs 3+6+7 9	Level III(a) Support Services 10	Level III(b) Special Needs 11
Live-in staff cont'd	Extremely dependent (350+)	$11.97-13.05	10.00	$7.00 $8.00	$51-60.00 (2-3 residents)	$2-10.00	Actual hrs. 6, 8, or 12 for 4, 3 and 2 persons respectively	A $64.97-$83.08 C $64.97-$83.08	Variable according to individual need	Average Cost A $1.00 C $5.50
Twenty-four Hour Staffed Residences	Very dependent (275-349)	$11.97-13.05	8.0-9.9	$7.00-$8.00	$56-80.00	$2-10.00	Approx. staffing pattern 5/6 staff &3/4 res 7 staff & 4/5 res 8/9 staff & 4/5 res 10/11 staff & 6/7 res 12 staff & 8 res	A $69.97-$103.05 C $69.97-$103.05	Variable according to individual need	Average Cost A $1.00
	Extremely dependent (350+)	$11.97-13.05	10.00	$7.00-$8.00	$70-80.00	$2-10.00	5 staff &5-9 res 7/8 staff & 4 res 9/10 staff & 5 res 11/12 staff & 5 res	A $83.97-$103.05 C $83.97-$103.05	"	Average Cost A $1.00 C $5.50
	Occasionally also for Somewhat dependent and	$11.97-13.05	3.5-5.4	$7.00-$8.00	$22.50-$44.00	$2-10.00	5 staff & 5-8 res 6 staff & 6-8 res 67 staff & 7-8 res 8 staff & 8 res or	A $36.47-$67.05 C $36.47-$67.05	Variable according to individual need	Average Cost A $1.00 C $5.50
	Quite dependent	$11.97-13.05	5.4-7.9	$7.00-$8.00	$44-64.00	$2-10.00	6 staff & 4-6 res 7 staff & 5-7 res 8 staff & 6-8 res	A $57.97-$87.05 C $57.97-$87.05	"	"

APPENDIX 8

Needs of the Elderly Retarded

Older retarded people have a range of needs of both a developmental and supportive nature: as they approach old age, these needs are not dissimilar from the basic needs of other aging people. For some of the elderly retarded, residential services can be provided by adding supports and resources to existing group homes to meet special needs. For others, the specialized residential programs proposed in Chapter V will be necessary.

1. Health care needs: planned periodic physical check-ups with particular attention to opthalmological and audiological assessments, podiatric care, regular dental care.

2. Physical exercise: the importance of incorporating physical activity into residential programs for aged persons must be emphasized. Recent research suggests few interventions offer as much prevention of disability as the use of regular, properly planned exercise for the elderly.

3. Counselling and education for aged: counselling on retirement, what it means to grow older, preparation for loss of relatives and friends, etc.

4. Social contact: opportunities to expand friendships among peers through citizen advocacy programs, discussion groups, weekend exchange visits (home-to-residence and residence-to-residence), attending religious services, etc. Meeting this need must include outreach to individuals living at home.

5. Homemaker support and respite care: support to elderly parents or caregivers to allow them holidays.

6. Living options: a variety of residential setting are needed, including small specialized group homes, boarding homes, access to senior citizen housing.

7. Relocation planning: the client must be involved in decisions about relocation. Involuntary relocation of aged persons is known to be associated with depression and withdrawal resulting from loneliness and loss of social role.

8. Transportation systems, particularly in rural areas: requirements often include special transport services, such as specially equipped vans or organized volunteers.

9. Employment or suitable day activities: developmental activities incorporated into workhop program geared to needs of aging individuals.

10. Guardianship, protective services, advocacy programs: as many parents age themselves, they feel legal guardianship of a developmentally handicapped "child" is required. Protective services as offered by Adult Protective Service Workers are an alternative for some individuals, as is the presence of an advocate in the support system for an elderly individual.

APPENDIX 9

Types of Behavioral/Emotional Disturbances among the Developmentally Handicapped: One Approach to Classification

Providing residential services to developmentally handicapped persons who have behavioral/emotional problems requires classification of the various types of behavior they engage in. There are many approaches to such delineation, including several sets of diagnostic categories; all are open to considerable debate.

The categories suggested here represent an attempt to set parameters for discussion purposes; they are listed alphabetically.

1. Aggression against persons.
2. Aggression against the physical environment (e.g., throwing, breaking, hitting, biting, feces smearing, arson).
3. Aggression against one's self (self-injurious behavior).
4. Aggression - verbal (e.g., temper tantrums, shouting, crying, swearing).
5. Hyperactivity.
6. Mannerisms - bizzare, stereotyped, repetitive movements, etc.
7. Mild inappropriate behavior, other (e.g., attention seeking, mimicry).
8. Neurotic behavior (e.g., anxiety and fearfulness, mild depression, obsessions, and compulsions).
9. Nonconformity to other norms and rules including anti-social behavior (e.g., lying, cheating, stealing, running away, sexual perversions, other "criminal" behavior).
10. Psychotic behavior (e.g., delusions, hallucinations, severe depression, though disorders, flight of ideas).
11. Withdrawn behavior and hypoactivity.

APPENDIX 10

Environmental Analysis and Problem Behavior

As yet we do not know the ideal environment in which to achieve a specific behavioral outcome. But paying more attention to environmental design may prevent some behavior problems or reduce their intensity, frequency, or duration. Moreover, an analysis of the stimuli that seems to elicit problems in any particular environment may suggest simple solutions that obviate the need for other programs, which may have uncertain outcomes.

Such an analysis would need to provide a variety of information including but not limited to:

1. Baseline data on the frequency of the problem behavior.
2. Data on various environmental stimuli that may elicit the behavior. For example:

    (a) In the social environment, possible stimuli may include:

        (1) The presence of certain persons.
        (2) Certain behavior of other people.
        (3) Relationships to daily routine and schedule.
        (4) Lack of adequate programming and activities.
        (5) Excessive programming and regimentation, which reduce opportunities for choice.
        (6) Lack of positive social reinforcement and attention from the staff, perhaps because of changed staffing patterns or activities.

    (b) In physical environment, stimuli may include:

        (1) Inadequate space.
        (2) Inadequate privacy.
        (3) Lack of sensory stimulation.
        (4) An excess of certain kinds of stimulation (high noise level, constant television viewing, etc.).
        (5) Lack of individual possession.

    (c) In the internal cognitive and physiological environment, stimuli may include:

        (1) Internal physiological precipitants, such as gastrointestinal upsets.
        (2) Frustration resulting from an inability to communicate feelings or requirements.
        (3) Inadequate reception of external stimuli, particularly among clients who are sensory-deprived.

3. The consequences of engaging in problem behavior. (Staff sometimes inadvertently reinforce problem behavior by providing reinforcement, particularly attention, that is available in other circumstance. Other residents and persons in the community may also reinforce undesirable behavior).
4. The frequency of reinforcing events and the behavior that they follow. (There is substantial evidence that an environment providing few positive experiences for the persons who live in it is one in which frequency of problem behavior is usually high).

APPENDIX 11

Advantages and Disadvantages of Moving Disturbed/Disturbing Clients to Specialized Residential Programs

Advantages

1. Opportunities for models of inappropriate behavior to have an adverse influence on the behavior of fellow residents may be reduced.
2. Other clients programming may suffer less disruptive from staff time being required to attend to the problem behavior.
3. A reduction in the quality of life of the other residents may be avoided.
4. An adverse effect on staff morale, which may in turn result in less effective programming, time lost, staff turnover, etc., may also be avoided.
5. If the behavior includes aggression directed at other persons, a change removes the possible danger of physical harm to other residents and staff.
6. If the problem behavior occurs outside the residence (or is known there), a move may prevent a community response that could jeopardize the existence of the program.
7. Specially trained and experienced staff can be brought to bear on the problem more intensively.
8. Removing the person from the environment and reinforcers that are eliciting and maintaining the behavior may provide a set-out from reinforcement of the undesirable behaviors as well as opportunities for acquiring more adaptive and socially acceptable behavior.

Disadvantages

1. An environment in which all residents frequently display undesirable behavior is one that provides substantial reinforcement for existing problems and numerous models for the development of new ones.
2. The frequency with which desirable behavior is modeled in a specialized program may be low.
3. As a result of the high frequency of undesirable behavior, the entire environment may become a discriminative stimulus eliciting such behavior.
4. A move to a different environment may disrupt other adaptive behaviors, particularly those that have been recently acquired.
5. The cost of providing such specialized programming would be substantially higher than the cost of more conventional residential services.
6. Perhaps most critically, a substantial body of research indicates that maladaptive behaviors that are eliminated in one environment will frequently reoccur in a different environment, particularly if the latter is the environment in which the behavior had previously manifested itself strongly. In other words, generalization often does not occur, and when the person is returned to his or her regular environement, the behavior reappears.

Additional research aimed at providing empirical evidence on the effects of segregated and integrated approaches on persons with problem behaviors, on other clients and on staff may well be worth undertaking.

APPENDIX 12

SPECIALIZED RESIDENTIAL SERVICES NOW AVAILABLE IN ONTARIO FOR PEOPLE WHO ARE SENSORY-IMPAIRED AND DEVELOPMENTAL HANDICAPPED

FOR THE HEARING-IMPAIRED

Location	Sponsorship	Type of Accommodation	Number of Residents	Type of Client Admitted
London	LDAMR	Group home	8 adults	Hearing-impaired developmentally handicapped
Peterborough	Private board	Group home	8 adults	"
Belleville	Private board	Group home	8 adults	"
Toronto	Ontario Mission of the Deaf	Two homes	6 adults	Hearing-impaired who may have mild developmental handicap
London Milton Belleville	Ontario Mission of the Deaf	Six group homes, in the vicinity of three Ministry of Education Residential Schools for the Deaf	(20) children	Deaf with other handicaps, including retardation, learning difficulties, behavioral/emotional problems
Toronto (OCCD)	Ontario Community Centre for the Deaf	Two adult residences (apartments in community center)	(18) adults	Some low-functioning deaf with other handicaps
	"	One children's residence	(20) children	Deaf with other handicaps; explicitly children discharged from Facilities.
Picton	Mental Retardation Facilities	Unit for the deaf	34 adults	Fairly high-functioning clients (many deemed borderline developmentally handicapped)
Cedar Springs Woodstock Orillia Smith Falls	"	Special units for deaf adults	64 adults	"

FOR THE VISION-IMPAIRED

Location	Sponsorship	Type of Accommodation	Number of Residents	Type of Client Admitted
Hamilton	CNIB	Semi-institutional	20 (total of 90 in residence)	High-functioning blind from Facilities
Brantford	W. Ross MacDonald School for the Blind (Ministry of Education)	Deaf-blind unit	43 children	Functional mental retardation in some cases
	"	Total stimulation unit	8 adults	Multihandicapped blind
Toronto	MTAMR	Group home with sighted clients	4 adults	Mild and moderately retarded from Facilities
Ottawa	Cheshire Homes	Group home	8 adults	Blind multihandicapped
Ottawa	Private operator	Group home ('Total Communication Home')	8 children	Vision and hearing-impaired
Belleville	Private operator	Group home (Suzie's Place)	5 children	Developmentally handicapped bline
Cedar Springs Orillia Smith Falls	Mental Retardation Facilities	Special units for blind	48 adults	On average, fairly low-functioning clients (including severely and profoundly developmentally handicapped)
Smith Falls	Mental Retardation Facility	Two special programs	32 adults	Blind

Summary of beds available in specialized residential programs

For hearing-impaired children	56	
For vision-impaired children	13	
For multisensory-impaired children	51	
TOTAL	120	120
For hearing-impaired adults	146	
For vision-impaired adults	112	
TOTAL	258	258
COMBINED TOTAL		378

APPENDIX 13

The Needs of Multihandicapped Clients

The following list of needs for clients who are both developmentally handicapped and sensory-impaired can provide a basis for guidelnes in the development of community residential servics, including shift-staffed homes and specialized family care, for children and adults. Assumed as key elements in program design are the developmental approach and the use of individual program plans to help clients achieve their maximum potential.

Needs of Vision-Impaired Clients

1. Vision assessment: periodic opthalmological and/or optometric screening and assessment to plan programming for the client, determine residual vision, etc.
2. Sensory awareness training: comprehension of sensory stimulation.
3. Auditory training: meaning of certain sounds in the environment.
4. Mobility and orientation training: the mechanics of movements, caning, cueing (use of sound from carpets, floors, etc. for orientation).
5. Remedial communication: receptive and expressive language, use of gestures, and nonverbal communication:

    (a) Simplified Braille.
    (b) Training in use of tape recorder.
    (c) Language stimulation - encouragement of abstract thinking.

6. Remedial exercise:

    (a) Body awareness and body concept.
    (b) Gymnastics.
    (c) Swimming.
    (d) Massage.
    (e) Horseback riding.

7. Life skills training, which includes:

    (a) Tactile contact because of difficutly in imitation.
    (b) One-on-one support in social skills training, self-care skills, etc.

8. Remedial education: especially necessary for adults who receive no formal education because of their handicap.
9. Behavior training: the tendency for maladaptive behaviors to develop when blindness is a handicap are high and the need for behavior-management therapy is often critical.
10. Location in residential neighborhood: near transit, with sidewalks to permit independent mobility.

Needs of Hearing-Impaired Clients

1. Hearing assessment: includes otolaryngological - (ENT - dealing with physical health of the ear) and audiological (evaluation and measurement of hearing ability) assessments that can be interpreted in terms of daily activities and used in program planning. Assessment of hearing must be periodic to determine if handcap and/or requirement for hearing aid has

changed. Rehabilitation of hearing loss is an ongoing responsibility, as is attention to ear health.

2. Vision assessment: periodic assessments are necessary because the incidence of the onset of blindness is higher among the developmentally handicapped than among the "normal" population. Periodic assessments are also necessary to ensure early diagnosis of Usher's Syndrome.
3. Language learning and communication: the need is not only for children. Many deaf persons graduate from school programs or leave provincial Facilities with inadequate methods of communication. Hence, remedial communication training is often a priority. Three basic approaches include:

   (a) Oral - traditional oral method, meaning speech and speech training.
   (b) Aural - amplified hearing method using residual hearing with hearing aids.
   (c) Total communication using fingerspelling, manual sign language employing either Manually Coded English (MCE) or American Sign Language (also called Ameslan or ASL).*

4. Equipment:

   (a) Personal equipment related to communication (e.g., hearing aid, telecommunication devices for the telephone).
   (b) Safety devices such as flashing lights and smoke alarms.
   (c) Training in the use and maintenance of equipment, particularly hearing aids.

5. Use of an interpreter: many deaf individuals who use a sign language system to communicate have very limited understanding of the English language. Children and adults need to be dealt with by a person with adequate communication skills with the deaf when in contact with them, for example, a case manager or a workshop job-placement officer.
6. Life skills training: one-on-one training is particularly necessary where deaf persons have spent many years in large residential settings without learning independence skills, personal hyiene, budgeting, meal preparation, etc. The develoment of maximum communications skills is a priority, as is the use of those skills in all training programs.
7. Mental health services: for deaf individuals with psychiatric illness and behavioral/emotional problems. Social workers and mental health professionals who can communicate with the deaf are needed.
8. Remedial education: the learning process for the hearing impaired of average intelligence is longer than normal. Remedial or compensatory education needs to be available well into early adult years. (This is at variance with current practice of beginning vocational placement at the school-leaving age of 18 or 19).

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* A variety of sign languages are used in English, for example, Pidgin Sign English, Signed English, Siglish, Seeing Essential English, etc. These are referred to as MCE. Educational settings generally use a form of MCE with speech. In the deaf community, however, American Sign Language, which is a distinct language from English, is widely used. ASL and MCE, although different languages, both depend on the use of space, facial expressions, the direction of signer's eyes, and other body movements to aid in communication.

Needs of Clients with Multisensory Impairment

The needs of people with multisensory impairments are extremely varied because they depend upon the extent of useful vision and residual hearing as well as the individual's adaptive skills. Intensive one-on-one programs are necessary, and individuals may require additional assistance to make use of services available in the fields of vision and hearing care. Most of the supports detailed in the two preceding sections are also needs of the multisensory-impaired. They can be summarized as:

1. Vision and hearing assessments.
2. Sensory awareness training.
3. Auditory training.
4. Mobility and orientation training.
5. Language learning and communication (including intervenor services - the provision of manual communication to transcribe information to deaf-blind individuals).
6. Remedial exercise.
7. Life skills training.
8. Remedial education.

APPENDIX 14

Descriptions of Physical Handicaps Frequently Associated with Profound Retardation

ORTHOPEDIC HANDICAPS

Spastic Cerebral Palsy

- Spasticity is marked by consistent increased muscle tone.
- Voluntary control of movement is impaired.
- Muscles contract too vigorously when being stretched or elongated.

The Rigid Form of Spasticity

- Disorder is characterized by widespread damage to the central nervous system and usually associated with severe mental retardation.
- Rigidity is a persistent, exaggerated resistance to movement and interferes with:

  1. The development head control.
  2. Reaching and supportive reaction of arms.
  3. Ability to sit securely with good posture and balance.
  4. Ability to sit normally.
  5. Ability to creep.

Spastic Diplegia or Paraplegia

- Involvement is primarily in lower trunk and legs with much less in upper trunk and arms.
- Head control and speech may be good, but eye coordination may be impaired.
- Movements are slow and labored and interfere with daily life as above (1 to 5).
- Depending on the severity of the spasticity of the upper trunk these persons do learn to walk but with impaired patterns.

Spastic Quadriplegia

- Involvement is generalized and includes the trunk and all four limbs.
- The head, rather than merely lagging, may actually pull back with gravity, preventing free head-turning or head-lifting to view surroundings.
- Rigidly flexed arms and fisted hands cannot reach forward.
- When bathed or cuddled, a person with this handicap is unable to respond with his or her body and thus seems unresponsive, which interferes with personal relationships.

Spastic Hemiplegia

- One side of the body is affected.
- Affected hand is fisted, and affected leg cannot kick.
- Head may be turned from affected side.
- The involved side contracts reflexively, moving the limb into the spastic pattern.
- If the problem is not corrected, the person has a hemiplegic gait, which can convey the impression of hyperactivity (the gait is fast as the person attempts to keep balance in walking).

The Athetoid Form of Cerebral Palsy

- The characteristic is frequent involuntary movements that may produce atypical and sometimes bizzare body movements and facial grimaces.
- Lesion in the brain is deep and affects control of automatic movements and posture.
- Hearing defects are often found in this form of cerebral palsy.

Four Groups of Athetosis

1. Athetosis with spasticity: muscle tone fluctuates between normal and hypertonus.
2. Athetosis with tonic spasms: muscle tone changes from low to high; extreme postures of flexion and extension.
3. Choreoathetosis: low to normal, and low to hypertonic movements are largely involuntary and disorganized.
4. Pure athetosis (rare): hypotonic to normal distal limbs have slow, involuntary writhing.

Effects of Fluctuating Muscle Tone

- Tongue thrust; open-mouth effect on eating, respiration, and speech.
- Problems with visual attending and focusing on environment.
- Arms usually more involved than legs.
- Hyperextension of fingers in grasping, causing withdrawal reaction; result is inability to hold onto objects.
- Poor coordination of antagonistic muscle groups; movement is random, irregular, and jerky.
- Extremes in motion (midrange activities and most difficult).
- Extreme effort causes associated reactions and drooling.

The Hypotonic Form of Cerebral Palsy

- Form is relatively rare.
- Muscle flaccidity is very marked.
- Motor milestones are considerably delayed.
- Mental retardation is frequent.
- Person often develops spasticity or rigidity within short span of time.
- Some persons with this handicap become athetoid in later stages of development.
- Effects include:
    1. Flat chest, hips that are flexed, abducted, and externally rotated (keeping body in this position too long leads to hip dislocation).
    2. Shallow breathing; little sustained phonation.
    3. Rag doll appearance.

Spina-Bifida or Myelodysplasia

Spina-Bifida comprises abnormalities in the spine (vertebrae) mainly a separation or nonclosure of the bony vertebral arch, which encases the spinal cord, during the early stages of development. The most important abnormalities are those of the nerves that originate in the spinal cord and go to the muscles of the lower extremities, the bladder, and the rectum, as well as to the skin of these body parts.

Myelomeningoceles

Of persons with any of the four types of Spina-Bifida, those with myelomeningoceles are most likely to have multihandicapping conditions. This condition implies a cystic lesion of the neural tissue and a malformed spinal canal. Motor weakness, varies from minimal to severe, correlating with the level and extent of the lesion. Sensory loss and lack of control over bowel and bladder are present. Hydrocephalus is frequently associated with this condition.

Hydrocephalus

This condition is caused by a dilation of the lateral ventricles in the brain, which may begin toward the end of intrauterine development. Normally, cerebrospinal fluid, which is produced within the ventricles, flows slowly through a series of channels to the blood stream; in hydrocephalus this pathway is totally or partially obstructed and the pressure inside the brain becomes high.

Effects of Spina-Bifida and Hydrocephalus

- Paralysis and deformity.
- Involvement of muscles and nerves varying from minimal to extensive according to the level and extent of the lesion.
- Resulting deformities of the extremities and trunk, i.e., scoliosis, lordosis, kyphosis, etc.

SEIZURES

A seizure is a disorderly discharge of electrical impulses in the brain. It is a symptom of disturbed brain function. Physicians use the term epilepsy to describe recurring seizures of unknown origin. Persons with developmental handicaps may experience eight types of seizures.

Generalized Seizures (originate in deeper centres of brain that control the whole body)

Absence Seizures (petit mal)

- Usually a momentary lapse of consciousness lasting 5 to 15 seconds.
- May be of high frequency (50 to 100 per day).
- In adolescence, usually disappear or convert to a different type.

Myoclonic Seizures (infantile spasms)

- Originate deep in brain and involve the whole body.
- Onset in infancy, three to twelve months.
- May be preceeded by short cry, laugh, or giggle.
- Marked by head bending toward chest, arms stretching upward, thighs bending toward abdomen.
- Very brief and of high frequency.
- Often difficult to control.

Akinetic (dropping spells)

- Characterized by sudden, extreme loss of ability to stand or sit upright. Usually, the person suddenly nods his or her head, slumps forward, or falls to the floor motionless. Muscle spasms may throw person to the floor.
- Loss of consciousness is temporary.

Tonic-clonic Seizures (grand mal)

- Most dramatic - hence the old term "grand mal".
  - The first, tonic stage lasts 4 to 30 seconds. It is a violent contraction of the body muscles; the eyes roll upwards, the legs extend, the arms flex, and the lungs force an expiration of air. The person falls to the ground and becomes cyanotic (blue). There is often profuse salivation (breathing through the saliva produces the so-called foaming). During the following clonic phase, the body and extremities jerk and twitch. After a few minutes the muscles relax, the person regains partial consciousness, and color improves. However, he or she is often confused and has a headache and muscular pain; a deep sleep may follow.

Partial Seizures (local or focal discharges of erratic electricity in specific centers of the upper part of the brain)

Focal, Motor, and Sensory Seizures

- May begin with stiffening or twitching of an arm or leg without loss of consciouness. Seizure may or may not spread into a generalized tonic-clonic seizure.
- May spread from one area to another on the same side of body, terminating in a tonic-clonic seizure. (The spreading is called Jacksonian March.)
- Motor seizures - any uncontrolled motor behavior from repetitive arm movements to loss of bladder control

  sensory seizures - see flashes of light, hearing rushing water, feeling heavy or light

Psychomotor Seizures

- The most complex kind of seizure - and the most likely to be mistaken for a behavioral problem or mental illness.
- May be simple stereotyped movements with a blank stare or a series of bizzare behavior out of keeping with the person's usual demeanor.
- Seen most often in adults, but sometimes in children.

Febril Seizures

- Account for at least 50 per cent of all seizures that occur during the first five years of life. May be major tonic-clonic seizures that occur with a temperature over 38°C (100°F) in children six months to five years old.
- Almost always benign and are not followed by epilepsy later in life.

Status Epilepticus (seizure that is an emergency)

- Occurs when person experiences one tonic-clonic seizure after another without recovering consciousness. Person should see a physician or be taken to an emergency ward and receive medication for seizure through the veins.

Staff Responsibilities regarding Seizures

1. To be able to observe and record seizures for diagnosis by physician.
2. To recognize and change conditions that increase risk of seizure activity (i.e., hyperventilation, intermittent light flashes, immoderate levels of exercise).
3. To know the common medications used to control seizures and their dangerous and unwanted side effects.
4. To be able to assist people during tonic-clonic, psychomotor, and status epilepticus seizures, taking action as necessary.

APPENDIX 15

CASE HISTORIES: THREE MULTIHANDICAPPED PERSONS

CASE HISTORY 1: MARK

Mark is a three-year-old boy born with hydrocephaly, a condition in which cerebrospinal fluid accumulates within the inner chambers (ventricles) of the brain.

This severe birth defect has given Mark serious brain damage and a number of other physical problems. His head is significantly enlarged from the pressure of the fluid on the soft, unknit bones of his skull in spite of the shunt procedure performed when he was an infant. (In this surgical treatment, a small tube is placed in the ventricle to drain the excess cerebrospinal fluid to other areas of the body.) He cannot move his head without assistance, and his muscles are very floppy. If his poor body posture is not aggressively interrupted, the weight of his elevated head pressing down on the spinal column will soon cause serious, abnormal back curvature. This deformity, called scoliosis, "scrambles" the lungs, heart, and digestive system because it causes excessive pressure on those parts of the body. Compression on the lungs makes breathing difficult and impairs sucking, swallowing, and chewing.

Poor body positioning, insufficient muscle tone, and the effects of gravity have pulled Mark's shoulders forward into a "closed flow" posture. His trunk will soon freeze into this haunched position, preventing the upper arms from functioning as they should. His other joints and muscles compensate pathologically and will soon deteriorate from lack of use; poor muscle tone converts to disuse atrophy when there is no opportunity for movement. Low muscle tone and a prolonged prone position are depriving Mark of the chance to bear enough weight on his hips to allow the sockets to form. If there are not joints, the hips may "subluxate". Unequal tone on each side of the body forces the hip on the floppy side to dislocate and contracts the muscles on the stiff side. The trunk and legs will begin to resemble an S-curve. When this happens, sitting upright becomes excruciatingly painful, and for some, nearly impossible without corrective surgery to replace the ball of the hip in its socket.

CASE HISTORY 2: CHRISTINE

Christine is a blind seven-year old who was born prematurely and experienced oxygen deprivation at birth. She has hyper-excitable muscles. When she attempts to move, they get too tight, locking her into a body position. One of Christine's major problems is an exaggerated startle reflex: any loud noise causes her entire body to stiffen into a bridge, with only the crown of her head and the soles of her feet touching the surface on which she is lying, and she cannot move out of this position without help.

This severe body arching also occurs when her mouth is stimulated, interfering with her ability to close her jaw and swallow in proper sequence. The jaw extension is accompanied by an abnormal bite reflex. She clamps down on anything that enters her mouth and is unable to release that bite voluntarily. Children with such problems are often deprived of opportunities to experience taste and texture. Caretakers frequently offer them only pureed food, which can be sneaked into the mouth and the spoon quickly withdrawn before the teeth clamp down. Mealtime is usually a fast "get-it-over-with" mechanical part of the day rather than a time for interaction between caretaker and client.

The same extension pattern affects Christine's arm position. She is usually seen in the "chicken wing" posture with shoulders pulled forward, elbows out and bent, fingers curled into tight fists and thumbs trapped in the palms of her hands. As a result, she cannot reach out, explore, and feel. Her learning environment is very limited.

Christine also has the asymmetrical tonic neck reflex or "fencer" position: sometimes her body pulls out of symmetrical alignment, one side in flexion (bent up), the other in extension (stretched out). Christine's body drifts to the right as if blown by the wind. Because the left leg is pulled so harshly inward, excessive pressure is placed on her left hip socket. Like Mark, she has what is called "windswept" hips. Dislocation of the left hip can occur rapidly because she has not placed enough weight on her hips to develop the sockets. Because her muscles are pulled unequally, her body is often twisted, shoulders in one place, hips in another. She is also a prime candidate for scoliosis and spinal torsion (S-curve of the spine).

Chrintine's spasticity increases her rate of metabolism; she consumes energy as quickly as she consumes food. Because she is very thin, her lack of movement causes her skin to break down from pressure on body prominences - it's as if she were paralyzed and unable to relieve the constant one-position pressure.

Christine also has seizure disorder that is only moderately controlled, and she experiences grand mal convulsions once or twice a year.

CASE HISTORY 3: PAUL

Paul is sixteen years old. He has cerebral palsy with the spastic muscle tone or quadriplegic distribution caused by an injury at birth.

Paul's family and teachers had few resources to help them give him what he needed to enhance his ability to gain control of his physical and social world and thus reach as independent a status as possible. He has spent most of his life lying flat on his back. Therefore, his early perceptions were ceilings or the upper halves of caretakers' torsos, neither of which offer adequate environmental stimulation. Paul has had very little opportunity to use his two strongest assets - good sight and hearing.

Many of Paul's joints are frozen into the positions to which his spastic muscles have pulled them. He has bent wrists, claw fingers, and contracted knees and elbows. Contractures are permanent shortening of muscles, tendons, or scar tissue; Paul's arms and legs have tightened and become fixed in bent postures.

The force of gravity on Paul's chest has flattened it like a pancake, leaving little space for his lungs to expand. Therefore, Paul catches cold frequently and has trouble recovering quickly; he also has difficulty expelling enought air across his voice box to produce audible sound.

Because of Paul's size, it is becoming very difficult to manipulate him into good body postures without stabilizing equipment and many strong hands.

APPENDIX 16

Areas of Program Emphasis for Profoundly Retarded Persons

Preschool Age	School Aged	Adult
Sensori-Motor Stimulation Stimulating sight, hearing smell, and muscular response Enriching environment and encouraging exploration of interesting and attractive surroundings	Sensori-Motor Development Identifying shapes, colors sizes and locations, and distances Identifying sound patterns, locations, tonal qualities rhythms Identifying textures, weights, shapes, sizes, temperatures Identifying familiar, aversive and pleasant odors	Sensori-Motor Integration Sorting, transferring inserting, pulling, folding Responding to music activities, signals, warnings Making personal choices and selections Discriminating sizes, weights, colors, distances, location, odors, temperatures, etc.
Physical Development Body positioning Passive exercising Rolling, creeping, and crawling Balancing head and trunk Using hands purposefully Standing practice Training for mobility	Physical Mobility and Coordination Practicing ambulation Overcoming obstacles; walking on ramps and stairs; running, skipping, jumping, balancing, climbing Using playground equipment Participating in track and field events	Physical Dexterity and Recreation Riding vehicles; participating in gymnastic-like activities and track and field events Marking with pencil; cutting with scissors; stringing beads; pasting and assembling Swimming and water play Using community parks, play-grounds, and other recreational resources
Pre-Self-Care Taking nourishment from bottle and spoon; drinking from cup and finger feeding Passive dressing; accommodating body to dressing; partially removing clothing Passive bathing; handling soap and washcloth; participating in drying Passive placement on toilet; toilet regulating	Self-Care Development Self-feeding with spoon eating varied diet; behaving appropriately while dining Removing garments; dressing and undressing with supervision; buttoning, zipping, and snapping Drying hands and face; partially bathing Toilet scheduling; indicating need to eliminate; using toilet with supervision	Self-Care Eating varied diet in family dining situation using eating utensils; selecting foods Dressing with partial assistance or supervision Bathing with partial assistance or supervision Using toilet independently with occasional supervision

Preschool Age	School Aged	Adult
Language Stimulation Increasing attention to sounds Encouraging vocalization Responding to verbal and non-verbal requests Identifying objects	Language Development Recognizing name, names of familiar objects, and body parts Responding to simple commands Imitating speech and gestures Using gestures, words or phrases	Language and Speech Development Listening to speaker Using gestures, words or phrases Following uncomplicated directions
Interpersonal Response Recognizing familiar persons Requesting attention from others Occupying self for brief periods Manipulating toys or other objects	Social Behavior Requesting personal attention Playing individually alongside other residents Using basic self-protective skills Playing cooperatively with other residents	Self-Direction and Work Using protective skills Sharing, taking turns; waiting for instructions Traveling with supervision Completing assigned tasks Participating in work activity centre program

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